Caring *for the* Carer

Learning report / October 2021

life changes trust
Creating better lives.

“There are certainly days when I feel overwhelmed, scared about what lies ahead and whether I will be able to cope.”

“I wanted to do the best for my mum but also needed time for myself which can make you feel guilty. I found that giving myself time out actually enhanced the quality of care I gave my mum. I would encourage anyone who is in a carer’s role to find something they enjoy and take time out to do it. They can go back refreshed and happier to give the care their loved ones need and the carer really wants to give.”

“The current COVID-19 situation has had a dreadful impact on my life. It has been the most upsetting, difficult, stressful and soul destroying time of my whole life.”

Contents

Background

Between December 2020 and February 2021, the Life Changes Trust, supported by the William Grant Foundation[1], awarded just over £300,000 through a new Fund to support unpaid carers of people living with dementia. The funding programme was developed based on learning about the impact of individual small grants for unpaid carers[2] and in recognition of the immense pressure on carers due to the COVID-19 pandemic.

Following an increase in the number of people taking on a caring role during the pandemic, there are now over a million unpaid carers in Scotland[3]. Research by Carers Scotland recently estimated that unpaid carers saved the Scottish Government £43 million each day of the pandemic.[4]

The additional caring responsibilities taken on by unpaid carers of people with dementia have been widely reported.[5] In October 2020 in a Carers UK survey, 87% of all unpaid carers in Scotland reported that they were providing more care than before. The average was 10 hours more care, with closure of local services, increasing needs of the person they care for and concerns about contact with paid health and social care staff among the reasons for this increase.[6] Carers who relied on family members or friends to provide a break were no longer able to do this due to restrictions as a result of lockdown. These were familiar experiences among applicants to the Caring for the Carer Fund.

---

[1] The William Grant Founwdation kindly contributed £25,000 to the Caring for the Carer Fund

[2] https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning and the Keep Well Fund for Young People with Care Experience

[3] https://www.gov.scot/publications/dementia-COVID-19-national-action-plan-continue-support-recovery-people-dementia-carers/pages/10/

[4] https://www.carersuk.org/scotland/news/unpaid-carers-save-scottish-government-43-million-every-day-of-the-pandemic

[5] https://www.alzscot.org/news/COVID-19-the-hidden-impact

[6] https://www.carersuk.org/images/News_and_campaigns/Caring_Behind_Closed_Doors_Oct20.pdf Survey of all unpaid carers, not just carers of people living with dementia

This funding programme supports one of the Trust's five investment priorities for people living with dementia and unpaid carers, **'I am empowered to do the things that are important to me'**. These priorities underpin the Trust's vision that all people living with dementia and unpaid carers in Scotland are valued as full and equal citizens, able to live good quality lives and receive the right support when they need it.[7] The Fund aimed to support the wellbeing of unpaid carers during the pandemic and focussed on the following three outcomes:

Coping with social distancing and isolation

Improving/ maintaining physical wellbeing and health

Improving/ maintaining mental health

It was evident from talking to carers and from written feedback that carers often feel guilty and selfish for thinking about themselves, and that a small amount of funding can bring an enormous sense of value and recognition to carers. Carers need to know that they are not forgotten or invisible and that the work that they do is appreciated by wider society. The fact that this Fund was focussed solely on carers helped them to feel that they had not been forgotten and encouraged them to apply.

The Trust received 458 applications for funding. This report has been written based on analysis of all applications and in-depth feedback from 82 carers, including interviews with 16 of them, reflecting on their experiences of applying for a Caring for the Carer grant. It highlights the benefits of a personalised small grants approach to supporting unpaid carers of people living with dementia and the impact that this approach can have on physical and mental health and social isolation.

We would like to thank all of the carers who took the time to write to us and those who kindly agreed to speak to us. We would also like to thank the decision panel members for their time and dedication.

---

[7] https://www.lifechangestrust.org.uk/sites/default/files/publication/files/Refresh%20Strategy%202019.pdf

Funding approach

Application process

The eligibility criteria for the funding were left deliberately broad to ensure that the funding was inclusive and could support a wide range of carers in different circumstances. Carers were eligible to apply for the funding if they lived in Scotland and cared for someone living with dementia for more than four hours a week, and were not paid for doing so. They were able to apply for anything that they believed would support them in the months to come. The Trust encouraged carers to discuss what they might apply for with someone they trusted, to help them identify how they could use the grant to support them in the best way possible.

It was evident through learning from the Trust's Individual Awards funding programme[8] that often carers do not think about themselves and their own needs, so the funding guidance was very clear:

> **'This Fund is for you, the carer. Therefore, we need you to think about yourself rather than about others.'**

To help carers think about what might best support them, the Trust provided some examples of what carers could apply for, for example:

- purchase or replacement of an item that helps the carer in the home
- technology to aid communication
- gym/exercise equipment
- hobby materials to pursue a pastime such as art or music
- subscriptions to a TV streaming service, website or magazine
- counselling
- a short break
- something that helps the carer to make better use of their garden or other outside space

---

[8] https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning

The maximum grant that carers could apply for was £1,000 and they were asked to provide evidence, in the form of a web link or quote, of the cost of the support or item they intended to purchase with the funding.

The Trust wanted to ensure that it reached as many carers as possible and, given the demands on carers' time, tried to make the application process very straightforward. The section in the application form requiring input from carers was kept to a maximum of four pages. The form focused on the intended outcomes for carers and the questions requested information about the current circumstances of applicants, what they wished to apply for and the difference that the funding would make to their life. Carers were asked to describe in their own words how they thought the grant could be used to support their wellbeing.

Applicants were able to contact a member of staff at the Life Changes Trust with any questions about their application or if they required further support or advice before completing their application. If a carer was unable to complete the application form electronically, staff would send a paper application to be completed and returned by post.

The approach aimed to be simple and flexible, also providing carers with the option, where needed, to request a telephone appointment to complete the application over the phone with a member of staff from the Trust.

The Trust did not accept applications from organisations on behalf of carers. Applications had to come directly from the carer either by email, by post or via the telephone. This was to ensure that the application expressed the wishes of the carer and was made with their consent.

As a funder, the Trust is always keen to learn if there is anything that could have made the application process easier for those applying. This was one of the areas covered in interviews with carers, who spoke about their experiences of applying for funding.

Carers overwhelmingly found the application process very straightforward, with the exception of one carer who was unable to download the form and admitted that she would have struggled to complete the application online due to a lack of computer skills. In this case the carer asked her son to assist her. As mentioned earlier, applicants had the option to complete a postal application or to do a telephone application with a Trust staff member. Whilst the majority (60%) of applications were sent in by email, just over a third of applications were submitted by post and 27 applications (6%) were completed by Trust staff following a telephone conversation with a carer. This demonstrates the importance of ensuring that funding is not promoted solely online and that carers have a range of options for applying.

One carer commented on the person-centred approach of the application form, which provided an opportunity for the applicant to explain their circumstances in their own words. She felt that staff had been very reassuring and approachable and the application form made it clear that the Trust had the best interests of the carer as the focus.

Interviewees acknowledged that asking for help can be difficult so it was important for carers that the staff they met from the Trust were helpful, understanding and friendly.

The interviews found that it was also important to carers that the funding would cover the full cost of the item and there was no expectation that the carer would have to top up the fund.

> **"It was good because you didn't have to contribute anything to the award. I applied for a respite grant from another organisation but it was not enough money to cover the cost of the respite."**

Having the opportunity to think through what would benefit them provided carers with the motivation to consider different items and reflect on what would work best for them. One carer commented that the funding provided the impetus to research alternative ways of doing art which had always been an important part of her life.

“The application process itself actually made me focus on my situation and realise that I was on the downward slope of giving up the one aspect of my life which provided me the light relief and respite from my carer’s situation.”

For carers who were hiding how they were feeling from other family members, the application process itself was often viewed as a cathartic opportunity to unload and write down how they really felt without feeling judged. For some carers, even the simple action of applying for funding enabled a small degree of hope in difficult circumstances. Imagining a less challenging time ahead brought positive feelings. The application process also prompted conversations where carers could open up and talk to family members about what would support them in their caring role.

> *“It was so helpful it got us talking about what mum valued, what she could look forward to, what mum and dad could do together. Mum often thinks and talks about what they cannot do - they cannot go out just now, everything seems impossible - this got us talking more about what was possible and bringing things to them if they could not go out... it was like a gift being given to her - she felt valued and special.”*

Assessment of applications

All applications were checked by Life Changes Trust staff to ensure they were eligible for assessment. Applications were then assessed by a decision panel comprised of four unpaid carers and two former unpaid carers from across Scotland who each had an understanding of caring for someone living with dementia. All of the panel members were familiar to the Trust and had worked with the charity previously. Panel members were remunerated for their time. They were asked to award funding to applications that demonstrated that the request for funding would meet one or more of the three key programme outcomes.

Meetings of this decision panel were held on a regular basis while the Fund remained open.

Panel members also had to be confident that the unpaid carer was the main beneficiary of the funding request.

Interviews with the decision panel members showed that, without exception, all of them were very happy to be involved and thoroughly enjoyed the role for many different reasons. Former carers were interested to see if support for unpaid carers had improved since their own experience of caring, whilst others were interested to see how other carers were managing during lockdown. For one panel member, being involved was a much-needed break.

> **“I really enjoyed doing this because I felt like it was a kind of respite for me, just to have an hour away and come and be involved. It was nice just to do something different because this last 12 months has been really tough.”**

Although the decision-making process was sometimes challenging, panel members found this to be a welcome distraction during the pandemic and they considered it a privilege to be asked to be involved in supporting other carers during such a difficult time.

The panel members welcomed the opportunity to provide this support because they felt that carers ***"...are normally forgotten about and in second place to the person they are caring for."*** It was important to them that carers and former carers were involved in the decision-making so that applications were carefully considered by those with similar experiences, albeit recognising that the dementia journey is different for every carer.

Panel members felt that they were able to bring a different perspective to that of the Trust's funding management staff. They also understood the difficulty that carers have in thinking solely about themselves rather than the person they are caring for, and felt a duty to advocate and use their experience and knowledge to support other carers.

> **"I had no idea what being a carer was all about until I was thrust into that situation. When you get a diagnosis of dementia, quite rightly it's all about the person with the illness but the family and people who are caring get pushed to one side at times. There was nothing out there to help me at that point. I had to go and look for things myself... I was never pointed in any direction. So it's important that the people who are going through it speak up not only for themselves but for the people that are going to be coming along, travelling this journey when I've finished my caring role."**

Panel members felt that their own experiences of caring helped them to relate to many of the stories told in the applications and this then helped them in their decision making. Skills that they had gained in their working lives were used as well as their own experiences of caring. They recognised that carers are often reluctant to look for help because of a worry that statutory services will think that they are not coping and the person with dementia will end up in a care home.

> **“I literally said that could be me that’s written that, I could relate to so many things that people were saying. Some of the stories were absolutely heartbreaking. Before I’d been through it I had no idea of how full on it can be. People think naively if you are caring you just get the person up in the morning, help them to the seat, give them their lunch give them their dinner, put them to bed they’ve no idea of all the in between. And also the emotional toll, it’s not just the physical toll, it’s the emotional toll that it can take on you.”**

Panel members were also aware of the impact of caring on physical and mental health, particularly during a pandemic, when friends and family were often unable to help due to restrictions and health and social care services were curtailed.

Due to the high volume of applications and the need for a quick turnaround, panel members worked in pairs to assess anonymised applications in batches over a three month period. Typically, each batch contained approximately 30 applications. Reaching a decision involved reviewing applications individually, discussing the applications with their assessment partner, then meeting with Trust staff to present their initial decisions. Trust staff were there to offer advice and guidance, and to ensure consistency across the batches, but the final decision on each application was made by the carers who brought different perspectives in discussions due to their varied experiences of the caring journey. Panel members found that much of the time they were in agreement about applications, which gave them confidence in their decision making.

> **“It’s our decision but we’re sensitive to what the Trust is thinking. We’re conscious that the money has to be given in the right way to people… We are trusted to say the money should be used wisely.”**

When asked what the most difficult or challenging aspect of being a panel member was, a number of issues were identified. Clearer guidelines for decision making would have helped, particularly at the outset when there was more debate about applications. The criteria were left deliberately wide but panel members felt that this was not necessarily helpful to them due to the huge variation in requests and amounts of funding.

> **"The whole process was quite a judgmental thing. That was a challenge... Having to make judgements on people but coming back to the core purpose of the fund. In the end I had to just keep that focus... Fell back on the criteria as a framework."**

Some applications were straightforward, but others didn't quite fit the criteria and panel members had to make a decision by weighing up the circumstances described in the application. Future programme guidance could have clearer parameters around multiple applications from a single household, part-funding of applications and a recognition that often items requested by a carer will also benefit the person living with dementia, thereby providing even greater added benefits to the carer.

> **"It was hard to say no to some of the applicants. The item was not really for the carer, it was for the person with dementia but in some cases you could see that it would also benefit the carer so that was difficult."**

Most of the requested items were intended to tackle isolation, which was not surprising to the group, particularly given the circumstances at the time. Some applications requested items that carers would not ordinarily buy for themselves because they preferred to keep money for emergencies, and panel members recognised the positive impact of being able to treat oneself as an important outcome of the funding.

> **"Some of the reasons that people gave for asking for things were nice, such a little thing can make a big impact and the fact that they cannot afford to get it for themselves. The fact that someone is looking out for them has given them a real boost."**

Panel members found that they were often able to bring their experience of items they had used which had helped them in their caring role.

> **"Someone asked for a recliner chair/sofa – I was able to say I have a recliner chair for my mum and it is a godsend and it enables us to not have to keep pulling her up, it enables us to be able to get her up safely. You have to look after yourself, you've got to be fit and well to be able to look after the person you are caring for."**

However, there were also items that panel members were not comfortable awarding funding for, such as herbal medicines, health food or some therapies, due to concerns about the possibility of the Trust being liable if something was to go wrong. Future funding programmes could include information that the grant cannot be used for this type of item.

Some of the applications were lengthy and panel members sensed that the person who was writing was getting benefit even from the process of applying for the funding.

> **“Maybe that was the first time they had actually put what they felt on the paper and rationalised and thought about it.”**

> **“It was a real eye-opener and brings things back to you. People seemed to be getting things off their chest, felt that someone was listening to them.”**

In some cases, panel members felt that people were applying for what they needed rather than what they wanted and a lot of items requested could potentially have been provided through a social care assessment. Again, panel members were able to use their knowledge to provide additional helpful insights.

> *“There were lots of people needing guided in the right direction for things they should be getting from social services. I was able to use my past experience to recognise that and put forward some ideas for signposting to other sources of support. It really highlighted the need for more involvement from social services in some of the cases.”*

The panel members also had concerns about some of the applicants due to information disclosed in applications and, in cases where they felt that additional practical or emotional support was required, they wanted to ensure that these applicants were signposted to other organisations that could help, such as Alzheimer Scotland, Age Scotland helplines and local Carers Centres.

> **“It was sad, some of them you could tell were really depressed. We mentioned that we were quite concerned about a few and we were reassured that people were offered direction to services that they might need. Although you don’t know the person, they sound really down, they really do need more help than just whatever they were applying for, they needed outside help. That was reassuring to know that that was being followed up.”**

Few applications were rejected or considered to be ineligible and the decision panel members had clear reasons for not funding these, for example, in cases where the item had already been purchased or installed prior to the application being submitted, or was for major construction work. Applications were also rejected if there was not a strong or clear fit with the three programme outcomes or the item would not provide the solution to the challenge highlighted. In other cases, the decision panel felt that the application was lacking in details about the person’s caring role which made it difficult to understand how the requested items would help to improve the person’s situation and wellbeing. Priority was given to unpaid carers with the most demanding caring responsibilities, who would receive the most benefit and impact from the funding.

Based on the discussions at review meetings, the Trust’s Funding Manager provided feedback to applicants who were unsuccessful. This often involved signposting carers to other sources of support.

The commitment and contribution from panel members throughout the decision-making process is testament to their resilience. Given the often harrowing content of some of the funding applications, the panel members received support and guidance from Trust staff. They reported that they felt adequately prepared and supported in their role assessing applications and that being able to discuss the anonymised applications with the funding team and ask questions further aided their decision making. They also had different ways of dealing with the content of the applications.

> **"I can detach myself very quickly... One or two cases were still with me for a wee while after I'd read them. I wish I could get out there and help these people. Or give health and social care a big shake."**

Those panel members that were current carers empathised with the COVID-19 restrictions facing applicants which meant that usual places and activities were closed and it was particularly difficult to find things for the person with dementia to do safely. Regular contact from the local Carers Centre had been a lifeline to one of the panel members.

> **"I feel that perhaps there could have been a bit more, just a phone call to say how are you doing or an email to say here is a contact number. COVID-19 was new to all of us and the rules were changing and it was only through [the local carers centre] that they offered to get PPE delivered to the house which was a godsend because I didn't know where to go, I was trying to buy stuff online and it was just a panic because everyone wanted masks and gloves."**

One panel member commented that she would have applied for funding for counselling if it had not already been available to her through other sources. She thought it was important to have individual ongoing support rather than just general information, especially at the beginning of a dementia diagnosis. In recognition of the significant difficulties experienced by unpaid carers as a result of the pandemic, the Scottish Government's COVID-19 Dementia Action Plan[9] committed to funding a National Dementia Counselling Service, hosted by Alzheimer Scotland, to provide professional counselling for people with dementia and for families and carers of people living with dementia who are adversely affected by the COVID-19 pandemic.

---

[9] https://www.gov.scot/publications/dementia-COVID-19-national-action-plan-continue-support-recovery-people-dementia-carers/

Despite the challenges, the decision panel found their involvement in the decision-making process to be very rewarding, particularly when Trust staff passed on feedback and photographs from some of the successful applicants demonstrating the impact of the funding award.

> **“It was really heartwarming to know that you’ve been able to help people because this has been a really rough year for carers, for everybody but when you’re a carer, the pressure has been really difficult at times. And I think just for them to feel recognised as well is a really big thing. So it was lovely just to hear some of the feedback on how grateful people were.”**

Awarding funds

A total of 458 applications were received, 457 of which were assessed by the panel. One application was ineligible for assessment due to it being incomplete, and the applicant did not respond to requests for additional information. A total of 802 individual items were requested within the eligible applications. The total amount awarded was £301,171 with 402 applications (88%) receiving funding. The highest amount of funding requested was £1,038 and the lowest £44.49, with the average grant awarded being £744. Almost half of requests (47%) were for funding of between £900 and £1000, and 24% of applications asked for the full amount of £1000. Thirty-five applicants (8%) asked for less than £400.

Further analysis of the applications can be found in the section below.

Staff hoped to make payments to successful applicants no later than two weeks after receiving the applicant’s bank details to ensure as quick a turnaround as possible.

Key challenges for carers during the pandemic

Carers were asked in their application to describe how the COVID-19 pandemic had impacted on their life, including whether their living circumstances had changed and whether their employment or education had been affected. Carers were also asked to describe some of the challenges they were experiencing and how COVID-19 had contributed to or exacerbated these pressures. Throughout the applications carers maintained what a privilege and honour it was for them to care for someone with dementia.

Information given in the funding applications provided a detailed insight into these additional challenges, which have been documented elsewhere.[10] Many of these challenges are not new to carers but were intensified as a result of restrictions and lockdown.

Applicants revealed how demanding their caring role had been during 2020, with one carer describing it as ***"firefighting".*** The impact of taking on additional caring tasks, lack of respite opportunities, lack of support from informal and formal networks, lack of sleep and difficulties accessing support and information had taken its toll on the physical and mental health and wellbeing of carers. These findings are consistent with the Carers UK survey which revealed the additional stress for carers at the time.[11]

---

[10] https://www.carersuk.org/images/News_and_campaigns/Caring_Behind_Closed_Doors_Oct20.pdf, https://www.carersuk.org/for-professionals/policy/policy-library/breaks-or-breakdown-carers-week-2021-report, https://www.alzscot.org/news/covid-19-the-hidden-impact

[11] https://www.carersuk.org/images/News_and_campaigns/Caring_Behind_Closed_Doors_Oct20.pdf

> *“As a carer, we have faced many challenges throughout the lockdown and coronavirus period. For example, due to healthcare and support visits being stopped, I had to take sole responsibility for learning medication and ensuring my mother-in-law was receiving this correctly. I also had to learn about dementia itself, to make sure I was supporting her the right way. This has been difficult as my mother-in-law requires 24-hour support and I have to be with her when she is eating and drinking for her safety. I have also had to conduct personal care which I have had no experience of before and so this was a very new experience for me. We also had Respite Care organised… so that we could have a break and recuperate. Due to the second lockdown, this was cancelled meaning we have had no break or time away from the house throughout the year. This was hugely difficult.”*

Physical health and wellbeing

Many applicants described being unable to find the time to exercise or being unable to exercise because of an increase in the needs of the person that they were caring for. Normal exercise routines had been prevented as a result of lockdown restrictions or because of the carer’s own health issues. An increase in caring hours also meant that many carers were simply too exhausted to do anything over and above caring. Many of the carers described the impact on their own physical and mental health and wellbeing of not being able to exercise.

> **“I need to maintain my fitness to continue my caring role. I have found my weight increasing, I have started having lower back problems and my mental health has deteriorated. I find myself in tears of tiredness and frustration most days. My greatest challenge is to maintain my fitness and overall physical and mental health so that I can face my future role as a carer, for however long that may be.”**

Deterioration in the physical health of the person being cared for also created additional caring duties, many of which could be physically demanding, such as lifting and moving the person with dementia. Applicants described taking on new roles and responsibilities that they had no training for, such as dispensing medication and many were managing multiple roles and multiple homes and caring duties. The usual outlets for relieving the stress of caring, such as gym, work, socialising with family and friends, had disappeared.

The evidence provided by carers also revealed that they were often not only dealing with the symptoms of dementia in the person they cared for, but also with comorbidity and multimorbidity, for example, colon cancer, stroke, arthritis, and prostate cancer. Added to this many carers indicated that they were coping with their own health problems, including arthritis, depression and anxiety.

> **“Lockdown was bad for everyone, but it coincided with the cancellation of a hip operation for myself which meant that I became more and more disabled as the months went on and so the caring duties that I had to do became more and more difficult.”**

Many applicants felt that they were on a downward spiral and one had been admitted to hospital twice in 12 months with stress that caused similar symptoms to a heart attack.

Mental health and wellbeing and social isolation

Carers applying to the Fund discussed the struggle to cope without the emotional support and respite that visits from family and friends often provided. Family members were living in areas with different COVID-19 restrictions, or were shielding themselves and, in some cases, were key workers who were understandably reluctant to visit in case they passed on the virus. Carers described the detrimental effect on their emotional wellbeing of not being able to see their children and grandchildren. Those carers who were in a ‘bubble’ with the person they were caring for felt isolated from other family and friends.

Carers UK reported that carers were losing on average 25 hours a month of support from family and friends and from care and support services, leading to significant stress.[12] In their funding applications carers described the physical and emotional toll this stress had taken on them, ranging from increased blood pressure and headaches, to being signed off work and being prescribed medication for anxiety and depression.

> **“With the additional impact of COVID, work, and as a Carer, I have been emotionally challenged, felt exhausted and stressed at times. I feel the impact of my caring role is physically and mentally affecting me. As my care role has become more demanding over the past year, more headaches, tension and anxiety due to current restrictions, my mum’s hospital admissions, care home service issues, staying over due to her health and wellbeing.”**

The applications also revealed the impact on mental health and wellbeing from being socially isolated, with carers reporting feeling lonely and overwhelmed with no variety in their day and nothing to look forward to. This appeared worse for carers living in rural areas. The usual activities that people participated in, such as going to the theatre, meeting friends, going out for lunch or coffee, were no longer possible due to fears of contracting COVID.

Loss of employment or being furloughed also emerged as a factor in the reduced social contacts among working carers and many reported missing the social aspect of working which sometimes provided their only form of respite.

> **“I was signed off work due to the stress this entailed and due to COVID-19 the avenues for help were either delayed or unavailable. I suffer from depression and on medication, so isolation with mum was very difficult. I lost my family, friends and work colleagues whom I confided in, all in a year.”**

---

[12] https://www.carersweek.org/about-carers-week/latest-news/posts-folder/2021/june/breaks-or-breakdown-new-report/

> *"One of the biggest challenges for me has been isolation from daily life, my working environment, which I loved, I was very active within my work and had many contacts and friends. I miss being involved with people and feeling valued as a person. I miss being able to just go out shopping or to see a friend at any time, or just go for a walk as I used to walk a lot. Another huge challenge is not having any conversation in my life now and days can feel very long. I cannot have any real conversation with my husband any longer. I now feel very sad and lonely most of the time now and this is not the person I was. Over the last 4-6 weeks I feel my mood has become lower and I feel very emotional much of the time."*

Applicants appeared conscious of the impact that caring was having on their own mental health but described how they had no choice and admitted that the main challenge for them was to keep going. Erratic sleep patterns came across as a significant factor in affecting carers' ability to function which, without the usual respite opportunities, led to carers feeling frustrated and inadequate, increasing levels of anxiety and depression. Many carers reported feeling 'numb', 'brain dead' and 'lost' and some have experienced what they described as ***'a complete meltdown'***.

> **"I am also finding day to day life a struggle dealing with my husband's decline in condition with not much interaction/ support from other organisations. I feel since Coronavirus my mental health has taken a massive dip... I feel I have lost my purpose in life and struggle to find who I am anymore."**

Applicants recognised the importance of respite in enabling them to continue with their caring responsibilities and some revealed plans for long overdue respite care which had suddenly been cancelled as a result of COVID. Many carers were elderly themselves and struggling with their own health issues. One applicant, a carer in her eighties looking after her husband, also in his eighties, had only managed to get two weeks of respite between March and November 2020.

Many of the funding applications reflected this need for a break, with carers applying for either accommodation costs for a few nights away in a hotel or for funding to cover the cost of care while they went to visit family or friends. Although restrictions at the time prevented people from going anywhere, just the thought of having something to look forward to in such a difficult year appeared to provide a boost.

> **"I feel that with a break I can gain my resilience back. It's somewhere close by so I know if there are any problems I can get home but it will provide me with some quiet time where myself and my husband can put ourselves first for a couple of days."**

The Independent Review of Adult Social Care (2021)[13] recently revealed that access to respite was a big priority for carers and should be viewed as 'integral to carer support'. The report recommended that the Carers Act should be amended to include a right to regular access to respite for carers to support them in carrying out their caring role and that a National Care Service should increase investment in respite provision.

Carers reported that lack of access to formal support services had removed vital links to information, support and respite and presented enormous challenges for them. They disclosed that they often struggled to explain their circumstances online and felt abandoned at times. The applications highlighted that activities which provided some respite were no longer operating due to COVID, whilst concerns around contracting the virus reportedly led to many carers making the difficult decision to stop paid carers coming into their home.

> **"My Mum also suffers from COPD and so was shielding, meaning we had to be extremely cautious in terms of sanitising everything and when the carers were re-introduced, ensuring the correct safety measures were taken. This was a very worrying and stressful period as she is high risk."**

---

[13] https://www.gov.scot/publications/independent-review-adult-social-care-scotland/

> **“Our regular carer came to our property with COVID symptoms leading to us having to isolate due to the risk of contracting COVID. After this I had such high anxiety about different carers coming in each day and the risk to us contracting COVID, we took the difficult decision to suspend our care support. This has been the most challenging time ever during my 10 years as an unpaid carer.”**

Applicants expressed difficulty accessing health and social care services and experiencing associated delays in assessments. The evidence from applications indicated that people with dementia who were diagnosed during the lockdown were unable to receive the level of support they were entitled to. Some applicants reported accessing health services remotely but found that describing symptoms and changes in behaviour was difficult and suggested that online or telephone consultations were not a viable alternative to physical appointments. Some described having care packages withdrawn and having to deal with what were often complicated health issues on their own. One carer had been waiting for months for an incontinence assessment and was paying for continence products to be delivered directly to the home at considerable expense.

> *“Additionally, just before COVID lockdown, when my Mum received a professional diagnosis for her dementia, we were finally entitled to Social Work intervention. Again, all done remotely and because it has been done remotely, there have been many delays in getting services/the help that my Mum required. Though I managed to get a dementia Link Worker, they have been unable to visit my Mum in her home throughout this whole year! She has been unable to access the groups/the support... She has been awaiting an OT assessment for her stairs etc. since the beginning of lockdown. Basically, I feel like my Mum and I have been holding our breath, waiting for this to come to an end and there is no end in sight.”*

One carer described how suspension of the activities that her husband usually participated in had led to a dramatic decline in her husband's physical and cognitive abilities. She told us that he had ***"gone completely downhill… It's not dementia that's killing him, it's the pandemic."*** She was understandably reluctant to admit her husband to a care home for respite due to risks around COVID and had tried unsuccessfully to get a referral through Social Work, who were only responding to critical care cases at the time. Pressure from health professionals to admit the person with dementia to a care home caused more stress, with carers describing their worry about the potential to catch the virus if moved to a residential or hospital setting. As one carer commented ***"We've contacted social services to see if we can get more help but there is a 12-week waiting list just for an assessment so that's not going to happen anytime soon."***

Marion's Story

Marion is in her sixties and has rheumatoid arthritis. Marion's mother has dementia and depression and still lives at home, with a lot of support from her family. During lockdown Marion looked after her mother seven days a week because her brother, who normally helps to care for their mother, was shielding.

The day centres that Marion's mother usually attends were closed, leaving no opportunity for respite. Her care package was also reduced as a result of staff shortages because of illness and cutbacks during the pandemic. Marion's mother is incontinent and because her overnight care was also reduced, Marion had to wash the bedding and change the bed each day. She was also responsible for shopping and paying bills.

Marion's mother was aware that there was a change to her routine during lockdown but she did not understand anything about the Coronavirus and why she was not allowed to go out. This resulted in her mood declining further. Marion tried everything to lift her mother's spirits but this took its toll and, exhausted, she phoned her GP and social services as she was at the end of her tether. Marion missed her friends and being unable to meet up and get a break away from her caring role made the situation worse.

> ***"Nobody seemed to be able to help and I just felt totally alone and trapped in a situation that I could do nothing about. I've had to contact my GP a number of times over the lockdown as I've just felt so low and completely overwhelmed and exhausted with the responsibility. My health has suffered as a result but I just have to keep going for mum's sake as the demands are relentless. It's not the same trying to explain problems over the phone and unless you're going through and living with the situation then nobody really understands how hard and emotionally draining it can be."***

Marion applied to the Caring for the Carer Fund because it gave ***"recognition to the situation that a lot of unpaid carers are in and the difficulties that they face"***. She decided to apply for funding to build a summer house in her garden because she thought that it would benefit both her physical and mental health.

> ***"Being in the garden provides a place where I can relax and switch off from everything. I can get away from the phone ringing and forget about all the stress for a little while. I especially like to sit out with a coffee and read or just to enjoy looking at the garden, and listening to the birds. I can only really enjoy sitting out when the weather's nice but by having a summer house I'll be able to enjoy the garden even when it's cold or raining. It would provide a little haven for me. It would give me somewhere to go to escape the demands of everything going on around me and just provide me with some peace and calm."***

Social connections

Carers who applied to the Caring for the Carer Fund described the many ways in which they had been supported during the pandemic. Friends, neighbours and local community groups appear to have been a lifeline in delivering food, prescriptions and a link to the outside world. Support from other carers through online activities and support groups or local carer organisations emerged as critical in the absence of family support due to COVID regulations.

> **"We are fortunate that all throughout lockdown, our family and some friends have kept in touch with us by window visits, Zoom (new skill for me) video calls, and our daughter gets our weekly shop and drops it at our door. Also, Our Community Kitchen has been delivering a hot meal 2 days a week to those most vulnerable in the local community."**

Many of the applications for funding were to purchase technology, laptops or iPads. Carers spoke about the desire to connect with family, friends, support organisations and healthcare providers. While some carers indicated that they benefited from regular online contact with support organisations and participated in online activities, this was not an option for everyone. Lack of access to technology or lack of confidence in computer skills meant that some carers missed out on vital support. In some cases, applicants suggested that the absence of external activities for the person they were caring for led to greater demands on their time and made it impossible for carers to participate.

It was clear from the applications that peer support had been invaluable in supporting carers to cope with the challenges of caring throughout the pandemic and many carers had received information about the Caring for the Carer Fund through local carer organisations or community projects. One carer explained that the virtual contact he had been able to maintain with family, friends and voluntary agencies had been vital in helping him to get through lockdown.

> **“I access a weekly Zoom Meeting for carers which has been a lifeline and it helps knowing I am not the only one experiencing these challenges.”**

However, the absence of face-to-face support from other carers was greatly missed by some applicants. Virtual support was not appropriate for everyone and was described as no substitute for face-to-face contact.

> **“Contact with my friends is via the phone but that’s not the same as meeting up for a coffee, a chat or in my case usually a good cry. At the start of lockdown in March, social work were not taking referrals for support so I was totally on my own. This impacted severely on my physical and mental health. I couldn’t talk to anyone without bursting into tears. I had no one to turn to and just had to try and get my head down and get on with it.”**

> *“I also miss meeting up with other carers that are in similar circumstances as myself. We used to meet up at the Dementia Centre every month and have a really good chat with what was happening with our partners and also find out any new information. It was good to see them all face to face. Now we have virtual meeting which is fine that we can still chat but not the same as getting out of the house and seeing everyone.”*

The emotional toll of caring

Applicants also described the enormous strain on relationships caused by living with and caring for someone 24/7, carrying out personal care and the challenges that came with a lack of sleep.

> **"Since COVID I cannot leave my partner for any period of time as it is too much of a risk. He can be up 4 or 5 times a night so my sleep can be as little as 3-4 hours some nights which impacts my emotional and physical health. The lack of sleep can have a profound effect on my ability to cope with things and I can be regularly in tears at the frustration and guilt I feel."**

Another common thread throughout the applications was the overwhelming sense of guilt felt by many carers. They felt pulled in all directions trying to care for the person with dementia at the same time as fulfilling other family caring duties. Carers wrote about the guilt they felt about neglecting partners, spouses, children and parents who were also often struggling with the impacts of isolation resulting from home schooling, working from home or being furloughed.

> *"I have two children which I hardly seen throughout lockdown as my main focus had to be my mother. I feel if I am completely honest, I have put aside my own needs, wants, luxuries, holidays, etc. since my mum was diagnosed but more so than ever, this year. Most importantly, I have put aside spending time with my children. I am so upset and embarrassed to admit I have deserted my family along the way."*

For carers of people with more advanced dementia the applications pointed to the added guilt and anxiety of considering putting the person they cared for into residential or nursing care during a pandemic.

> **"I thought my Mum was end of life and I was trying to soldier on to keep her at home as it seems too cruel for her to go into residential care during lockdown but now I don't know as the GP says she could go on a long time."**

Others described their guilt about not giving the best of themselves as employees due to combining paid work and caring.

> **"My employers have been great throughout the last 18 months, but I do feel guilty to my colleagues that I am not there working with them and doing my job in full at a very busy and difficult time."**

Feelings of guilt also appear to have led to carers being reluctant to ask for help. In their applications, some suggested they did not feel that they deserved to apply to the fund, despite recognising that they sometimes need to put themselves first to be able to continue their caring role.

Carers have faced many challenges in caring for someone with dementia during the pandemic without access to the usual formal and informal support networks and this has taken a considerable toll on their physical and mental health and wellbeing. In recognition of these challenges the Dementia and COVID-19 National Action Plan[14] sets out a range of measures to support carers, including a £500,000 fund to support local carer services move to supporting carers remotely, extra funding for short breaks for carers and a counselling service provided by Alzheimer Scotland to support carers of people with dementia emotionally with a focus on the impact of COVID and its lasting effects on families.

---

[14] https://www.gov.scot/publications/dementia-COVID-19-national-action-plan-continue-support-recovery-people-dementia-carers/

Deterioration in the health and cognitive ability of the person with dementia

Applicants described their shock at the rapid deterioration in physical mobility and cognitive ability in the person they were caring for and often spoke about feeling powerless to do anything to stop this rapid progression in symptoms. This reflects similar findings to Alzheimer Scotland's recent report on the hidden impact of the pandemic and an Alzheimer's Society report in September 2020 which revealed that 82% of respondents to a survey had reported a deterioration in the symptoms of people with dementia, particularly memory loss, difficulty concentrating, agitation/restlessness and stress or depression.[15,16]

> *"The difference in mum between what she was like last March and now, it's actually quite frightening how quickly things have deteriorated, her mobility because you can't get out. Her mobility wasn't great anyway but it's literally down to zero now. And it's the mental toll because they don't understand why you can't go out to the shops, they don't understand why things aren't open or why you've got to put a mask on. And it's not like when things are back to whatever normal is going to be, that they will go back to where they were because of the nature of the illness, it's frightening and you just feel so out of control because you can't do anything to slow it down."*

With no activities, groups or appointments to attend and with no social events, it was very challenging for carers to keep the person with dementia occupied during lockdown. Carers revealed that increased anxiety and depression in the person with dementia meant that they were more dependent on their carer for support, adversely affecting the relationship between them both. With no variety in their day-to-day life and with many seeing only one other person every day for months, the significant impact on the mental health and wellbeing of both carer and the person being cared for is understandable.

---

[15] Alzheimer Scotland 'COVID-19: the hidden impact' https://www.alzscot.org/sites/default/files/2021-05/Hidden%20impact%20Report_Updated.pdf

[16] https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf

> *"Prior to lockdown, he attended Men's Shed twice weekly and a day centre once a week. He could be left alone at home. His dementia has advanced considerably over the last nine months. I can no longer leave him alone. I can no longer attend the gym due to my caring role. As a result of isolation and my husband's deteriorating condition I have become clinically depressed. His language is most affected and conversation is very difficult now. Frustration at lack of communication is affecting us both."*

Carers also described increasing cognitive impairment in the person they cared for, including difficulty sequencing tasks, word finding difficulties, loss of confidence communicating and completing tasks independently. In the applications, carers often made links between the lack of stimulation from activities attended prior to COVID and deterioration in the condition of the person with dementia.

> **"The effects of lockdown and then contracting the virus have been quite striking on P. His ability to articulate his thoughts has greatly diminished and his mobility has been severely impacted. These are due to the lack of opportunity to get out and mix with others."**

> **"This lack of interaction from her support network and not seeing locals from her village has, in my opinion, accelerated mum's Alzheimer's and her speech is much more muddled and as a result she prefers not to speak. This breaks my heart."**

Despite the best efforts of many carers to stay in touch with support organisations, people with dementia often struggled to comprehend communication via online activities. This was especially difficult for those with hearing or visual impairments.

> *"My wife's condition has accelerated during the pandemic, she is no longer able to manage in the house and she gets confused and disorientated. She really needs more help, someone to take her out for a walk, or a club she could join but these supports are not available at the moment due to the pandemic. She is very hard of hearing, telephone and virtual groups would be too hard for her to hear and follow. Her fail safe is to say no to things and it is hard to get her to try, she does like company though and would respond much better to an actual person."*

Another big concern for carers was the impact on the physical mobility of the person they cared for as a result of being house-bound due to shielding and restrictions on travel. Carers reported an increase in falls due to balance problems as a result of decreasing physical mobility in people who had regular walking routines prior to COVID and they were concerned about the long-term impact of this. Many worried that the person they cared for would not regain their previous mobility. Carers reported that they were no longer able to leave the person with dementia on their own for any length of time to get out even for a short break.

> **"We have been forced to totally isolate to avoid upset and confrontation in public spaces. As a result, I can only confirm the validity of the 'use it or lose it' motto. Dad is less mobile; unsteady when he walks and I have to keep close to support his balance and mobility. His world is getting smaller all the time, which I find very stressful as he was the most active, fit person in prior years."**

Carers were also concerned about the increase in anxiety and agitation experienced by those they were caring for as a result of the restrictions on movement. They conveyed their worries and stress around trying to keep the person with dementia safe when they did not understand the rules around social distancing or mask wearing.

"My Mum doesn't understand the virus and the restrictions and thinks people are not visiting because they don't like her and is feeling paranoid about her neighbours and the care staff at the retirement home, refusing to accept help."

> *"If my dad was to go out of the house, he doesn't understand social distancing, he never remembers to wear a face covering and never sanitises his hands. This really worries me what if he gets the virus- will his immune system be able to cope with this?"*

For carers who had lost family members to COVID and other illnesses during the pandemic, being unable to hug anyone and grieving while explaining loss repeatedly to someone with dementia took a huge emotional toll.

The economic impact of caring during a pandemic

For some applicants, financial stress simply added to the existing stress of caring for someone with dementia. Many carers in Scotland already faced difficult financial situations due to their caring responsibilities and additional costs incurred through caring. With support services closing during the pandemic and informal support limited, often carers had no choice but to reduce their working hours or give up work to manage caring responsibilities. A Carers UK report in October 2020 revealed that 7% of carers had reduced hours to manage their caring responsibilities, and 7% had given up work to care since the COVID pandemic.[17]

---

[17] https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-sixmonths-on

> *"The only income I have is from the carer's allowance, and four hours a week I work at a café that a friend owns (when it is allowed to be open). I'm bringing in only 20% of what I used to earn and it is really bringing me down."*

Loss of income due to being furloughed, being made redundant, or through being unable to run a business appeared to not only have a financial impact but also an impact on self-esteem and confidence, anxiety about the future and loss of identity and purpose. Some carers were self-employed and ineligible for government support which only added to their stress levels.

> **"I had to give up my work to care for him and as I am not eligible for a state pension for another 4-5 years money is scarce and benefits do not cover all bills etc. This is an additional source of worry."**

This finding is consistent with the Carers UK report which revealed that 29% of carers in Scotland were struggling to make ends meet, while 10% reported that they were or had been in debt as a result of caring.[18]

In order to be able to stay in work it is important for carers to be supported by their employer and to be able to work flexible hours when they have caring responsibilities. One applicant described her experience:

> *"The biggest challenge and one of the most difficult times of my life was when my father had COVID and I did not have the support I really could have done with. My employer questioned the time I required off as my father was obviously self-isolating - which didn't mean my carer role stopped. I had to explain every aspect of my role during the time which was very unpleasant when I was so emotionally weak. I suffered from a lot of anxiety at this time."*

---

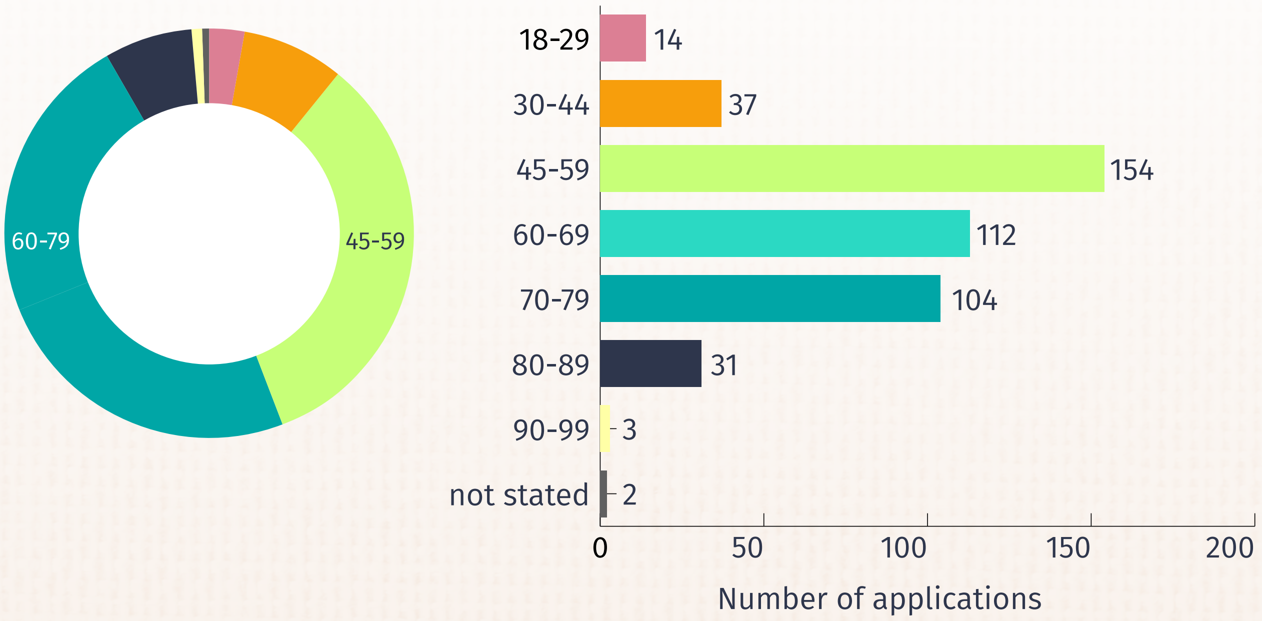
[18] https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-six-months-on

Who applied for funding?

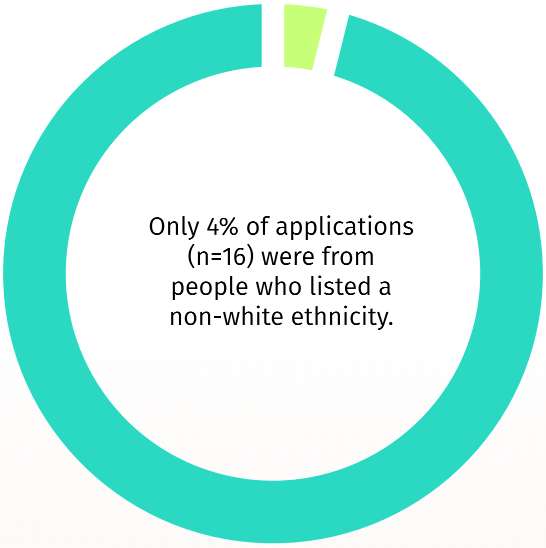
This section provides some demographic information about the carers who applied for funding.

Age group

Almost half of the 457 applications (48%) were submitted by those aged between 60 and 79 years old, however, over a third of applications came from 45-59 year olds.



Diversity of applications



The very low number of applications from people who stated their ethnicity as non-white might indicate lack of knowledge of the Fund amongst Minority Ethnic groups. The main way that Life Changes Trust advertised the Fund was through project partners, which included partners working with Minority Ethnic groups in Scotland, although their reach is likely to be limited. For example, the Minority Ethnic Carers of People Project (MECOPP), who support carers from the Black and Minority Ethnic communities operate within Edinburgh and the Lothians only. Other project partners are focussed in Central Scotland (Central Scotland Regional Equality Council), Aberdeenshire (Aberdeen Council of Voluntary Organisations) and Glasgow (REACH Community Health Project).

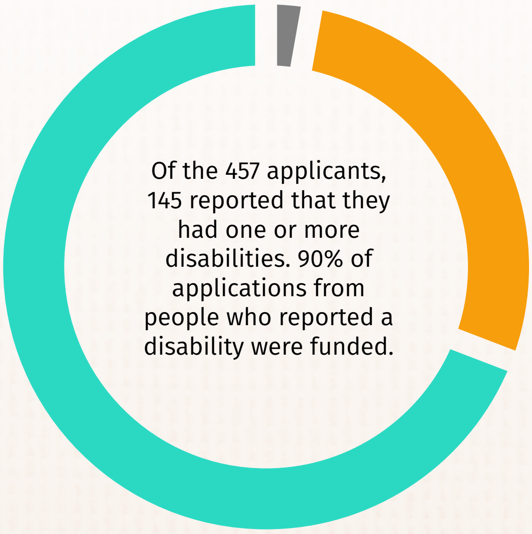
Low numbers of applications may also reflect cultural differences in seeking out help. Blake Stevenson's evaluation of the Life Changes Trust's dementia projects for Minority Ethnic Communities in 2020[19] highlighted the lack of a specific term for dementia in many ethnic communities leading to lack of understanding and awareness, along with a resistance to engagement with social and health care services through fear of discrimination or perception that services will be culturally inappropriate. Eleven of the applications received from non-white applicants received funding.

---

[19] https://www.lifechangestrust.org.uk/publications/evaluation-dementia-projects-minority-ethnic-communities

Disability

Applicants were asked to state whether they considered themselves to be living with a disability. The application was not prescriptive about the criteria and therefore reflected the applicant's own decision about whether they felt their lives were impacted by a disabling condition. The most commonly reported disabilities were those relating to mental health conditions and mobility. There were very few applications requesting items relating to mobility and pain management, for example physical therapy (3%), specialist furniture (3%) and a specialist wheelchair (1%). This may relate to these applicants already receiving these items and services, or, perhaps more likely, may reflect the nature of the Fund as something that was intended to give people a boost and not look to fill in gaps in service and statutory provision.



Of the 457 applicants, 145 reported that they had one or more disabilities. 90% of applications from people who reported a disability were funded.

Almost a third of applications who self-reported a disability recorded this as related to anxiety, depression and other mental health conditions (32%).

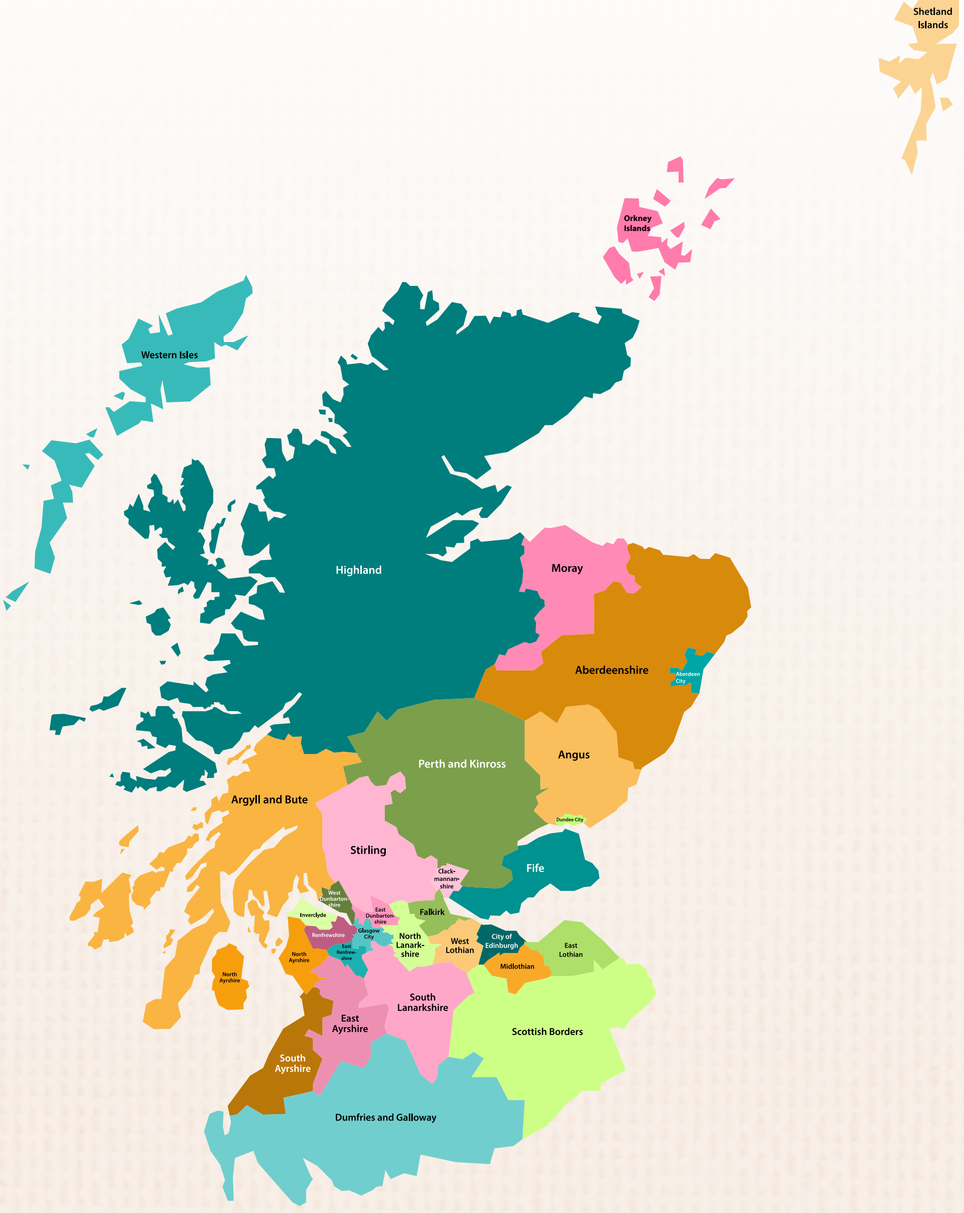
Nearly 50% of applicants self-reporting a disability had issues with mobility and functional movement.

Geography

Every Local Authority Area was represented in the applications, with the highest number coming from Edinburgh City and Highland. It is interesting to note that some areas with lower populations submitted relatively high numbers of applications. The Fund was promoted via project partners and wider networks of the Life Changes Trust. Areas such as the Western Isles have benefitted from active project work and therefore it is likely that people tended to be made aware of such opportunities. Information from interviews of beneficiaries of the Fund also reflected this, with one recipient telling us that she had been made aware and encouraged to apply by a professional from Alzheimer Scotland who had provided their post-diagnostic support service.

Number of applications from each Local Authority Area:

Edinburgh 66
Highland 54
Fife 42
Aberdeen City 33
East Renfrewshire 25
Western Isles 22
Glasgow 19
Dumfries & Galloway 17
West Dunbartonshire 16
Perth & Kinross 15
Falkirk 14
East Lothian 13
Dundee 13
Scottish Borders 12
North Lanarkshire 12
Inverclyde 10
South Ayrshire 9
Aberdeenshire 7
North Ayrshire 6
Midlothian 6
Argyll & Bute 6
Angus 6
West Lothian 5
Shetland 5
Renfrewshire 5
East Ayrshire 5
Orkney 4
Moray 3
East Dunbartonshire 3
South Lanarkshire 2
Stirling 1
Clackmannanshire 1



What did carers apply for?

The majority of applications made reference to the stated outcomes of the funding programme and almost half of these (48%) applied for an item that would support them with all three of the outcomes.

- Helping the carer cope with social distancing and isolation.
- Improving/maintaining the carer's physical wellbeing and health.
- Improving/maintaining the carer's mental health.

Just over half of the applications that requested funding for an item that would support two of the outcomes wanted to improve mental and physical health, possibly because carers understood the benefits on mental health of being physically active. Another 40% of applications looking for support with two outcomes asked for help with social isolation and mental health, demonstrating the impact on carers' mental health of being cut off from family, friends and work colleagues.

Of the applications that focused on one outcome only, almost half wanted support improving physical health, reflecting the difficulties that carers had in participating in exercise due to increased care responsibilities and lack of opportunities to get some time to themselves.

Where applications were related to a single outcome, we assessed the types of items requested. Where more than one outcome was chosen, we were unable to link an item to a specific outcome, and items may have been relevant to more than one outcome.

There were **ten** applications which mentioned **only outcome 1**: coping with social distancing and isolation. The most commonly requested items were home furniture and home improvements.

Thirty-two applications mentioned **only outcome 2**, improving and maintaining mental health. The most commonly requested items were iPads, short breaks and garden improvements.

Forty-one applications mentioned **only outcome 3**, improving physical health. The most commonly requested items were home furniture, garden improvements, iPads and gym equipment/bikes. Two applicants who requested tablets/computers referred to this being a means to enhance their fitness. Although not stated, it is possible that other applicants were looking for a means to get access to health and wellbeing information.

Main categories of items requested

The top 6 categories:

tablet or computer
130

garden improvements
118

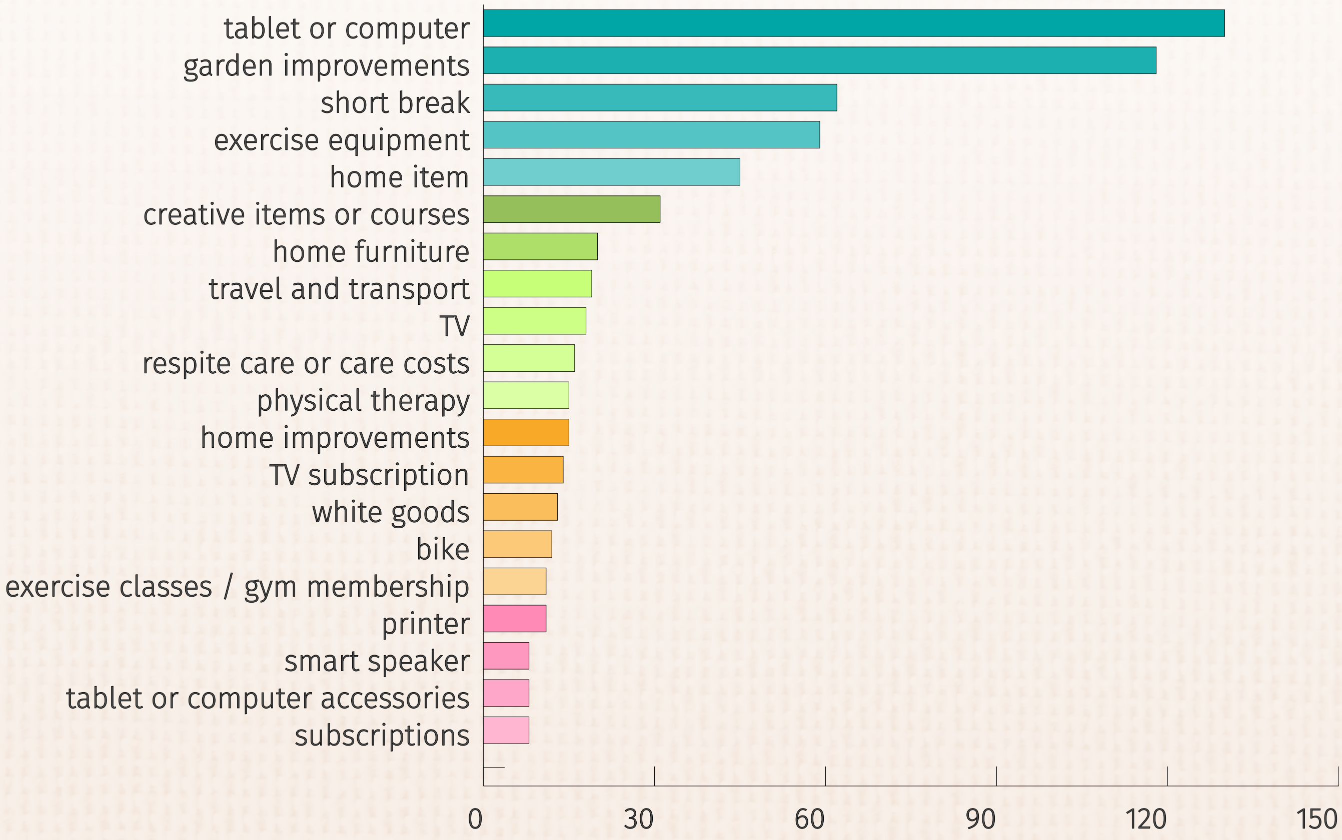
short break
62

exercise equipment
59

home item
45

creative items or courses
31

Top 20 Categories



Technology

There were 228 requests for items relating to technology, over half of which were for an iPad, tablet or computer. Other requests included, a digital photo frame, wireless speakers, echo show, air pods, security camera and broadband.

There were 8 requests for smart speakers (Alexa, Echo, Facebook portal) which tended to come from people in the 30-44 and 45-59 age categories.

It was evident from the applications and interviews with carers that technology was used for many reasons which often supported them in their caring role. Technology helped with online shopping, re-ordering prescriptions, attending virtual clinical and hospital appointments, banking, accessing resources, online carers groups, activities and fitness and keeping in touch with family and friends.

One carer applied for a large TV because she thought that the brighter screen and better sound would help her and the person she cared for to enjoy their programmes more because their eye sight and hearing had deteriorated.

A carer who wanted to be able to listen to music while his wife watched television applied for an Apple iPod Touch and some headphones. He felt that the device would give him some time to himself because it was portable so he could use it to listen to music around the house, or outside.

Carers also wanted technology to help them to stay connected to others.

> **“To be honest our video contact with our children and our grandchildren are a lifeline to us. It helps us so much and brings some lightness into the darkness.”**

Home and garden improvements

Overall, 219 requests were for items related to improvements to the home or garden. Carers requested funding to support adaptations that they needed to make their home safer for the person with dementia. In some cases, carers had decided to pay for adaptations privately given the waiting times for an occupational therapist assessment. These included installation of downstairs toilets, shower room renovations, underfloor insulation, flooring, wall cladding, a new kitchen and structural engineering drawings.

> **"I have decided to turn my living room into a bedroom so that it is keeping my husband on the same level and that he can be downstairs, and trying to get him engaged in things more on the downstairs level. He will have access to the back garden area and can watch me doing some gardening which I love and get some fresh air. So a toilet downstairs would be a God send."**

> **"I would like to apply for funding to remove carpet and replace it with vinyl flooring. My husband has episodes of incontinence and the stress this brings because of the constant cleaning of carpets is really difficult. I struggle with this aspect and have spent a lot of time on my hands and knees scrubbing the carpets and this has affected my mental health. I have to say that it is an aspect of caring for my husband that I find extremely challenging and he picks up on my stress when I am constantly cleaning up after him."**

There were 118 items requested relating to garden improvements. The three most common requests were for: furniture or garden features, such as benches and raised beds (43), buildings, shelters and heaters to improve comfort and increase use of the garden (35) and general improvements (16). Of these general improvements, five requests were for items specifically relating to improving accessibility to the garden. They were: replacing old garden stairs, paving, adding a handrail to the garden, installing a ramp and making the garden wheelchair friendly. It is feasible that these requests could have been covered by Care and Repair (for smaller items such as a handrail) or self-directed support. Unpaid carers are eligible for self-directed support to help them maintain their caring role under the Social Care (Self-Directed Support) (Scotland) Act 2013. The average cost of these applications to the Fund was: £703 (although the funding team recommended increasing the amount of one of the requests).

Although the funding programme was aimed at improving outcomes for carers, garden improvements also potentially benefited the person with dementia.

> **"I should like to apply for funding to improve our gardening experience by creating some raised beds to grow vegetables and a bench where we can take time to enjoy our time outdoors. These items will enable me to relax both physically and mentally whilst still fulfilling my carer role. It will make it easier to engage my mother in rewarding activities without creating more work/time commitment for me. Both of us will benefit from the physical activity and the family will, hopefully, be able to have fresh, healthy produce as the fruits of our labours. We will also have an area to relax together or for me to have some 'me time'."**

Furniture and home items

There were 78 requests for home items such as furniture, white goods especially washing machines and tumble dryers, as well as kitchen equipment, floor cleaners, cookers and mattresses.

There were an additional seven requests for specialist furniture, which covered items that might be considered eligible to be provided by statutory services or through self-directed support funds. These included riser chairs, hospital and electric beds, wheelchairs and mobility chairs. Although some were funded, requests for very specialist equipment were not, as the decision panel considered that the funding available would not adequately cover items to the standard required, and that they should be provided by the health authority.

There were two requests for contributions towards a person's rent costs. These did not receive funding from the panel.

> **"My husband has problems sleeping, is restless and keeps me awake, consequently I am finding myself very short tempered with him and I feel constantly tired. I just want a good night's uninterrupted sleep to recharge so I can continue to support, care and love my husband. By purchasing single beds for us both it will greatly improve my sleep and my mental wellbeing, enabling myself to care for my husband. If this sounds simple it really is. My daughter supports me and together we can care for my husband. I just need sleep to be able to achieve this."**

A man in his nineties who was looking after his wife applied for a lighter, safer vacuum cleaner.

> **"The one I have at present is very old and heavy to use. A new lighter cleaner would be beneficial to me and make it easier for me. A cordless vacuum would also be a lot safer to use."**

Hobbies and creative activities

There were 31 people who requested items relating to creative activities and hobbies. These carers were mainly from the 45-59 and 60-69 age groups. The most commonly requested items were art materials followed by craft materials.

Other requests included art classes, cameras, musical instruments and sewing machines. The individual nature of requests for jigsaws, a model railway baseboard, a pool table and a pottery workshop demonstrate the importance of having funding that the carer can tailor to their own needs and wishes.

> *"I only recently started to sew using a machine I inherited from my mother-in-law. If I'm totally honest, sewing has kept me sane and has greatly helped my mental health during our initial lockdown and the months since. I enjoyed making scrub bags for our local hospital and nursing homes. I also made facemasks for friends and family. I would love a new sewing machine & one that can do embroidery."*

> *"I would love to apply for funding to purchase a guitar and some books to allow me to get back into this once loved activity. It cheers me up and I can enjoy learning new songs and get my mind activated again. I always find it relaxing and it takes me to a different headspace. Music is one of the few things my mother responds to in a positive way and I smile when she smiles. When this form was sent to me it was only then, when I thought about my own needs, I realised just how much I had missed playing the guitar and would love to do so again."*

> *"I would like to buy some art materials, such as canvas, paper, paints and an easel, sketchbooks and brushes, plus a video camera and a laptop to make and edit films. I want to go out into the beautiful landscape for walks and do some drawings in sketchbooks as well as doing some filming. I then want to go into my studio and paint and do prints. This will support and improve, or maintain both my physical and my mental health, by not only getting me out into the fresh air and moving, getting exercise, but also help me to make some art which to me is very therapeutic."*

Travel and transport

There were 19 requests for items relating to travel. These items were most commonly requested by people in the 18-29 and 60-69 age groups and included driving lessons, mobility scooters and travel expenses, for example to visit family members and accompany them to appointments; and to pay for taxis that could take someone to group activities which would normally require a family member to drive them and stay for the duration. Less commonly requested items included replacement tyres, bus pass, car repairs or running costs or funds to purchase a car.

> *"An Intensive Driving Course would allow me to go beyond the quarter of a mile I am currently confined to. If I could drive I could help my mother without having to leave her alone in the home. I also would be better able to maintain friendships and see people which I currently cannot do. Learning a new skill would provide me with a challenge and assure me that I am not losing that ability. It would also improve my future employability."*

Personal development

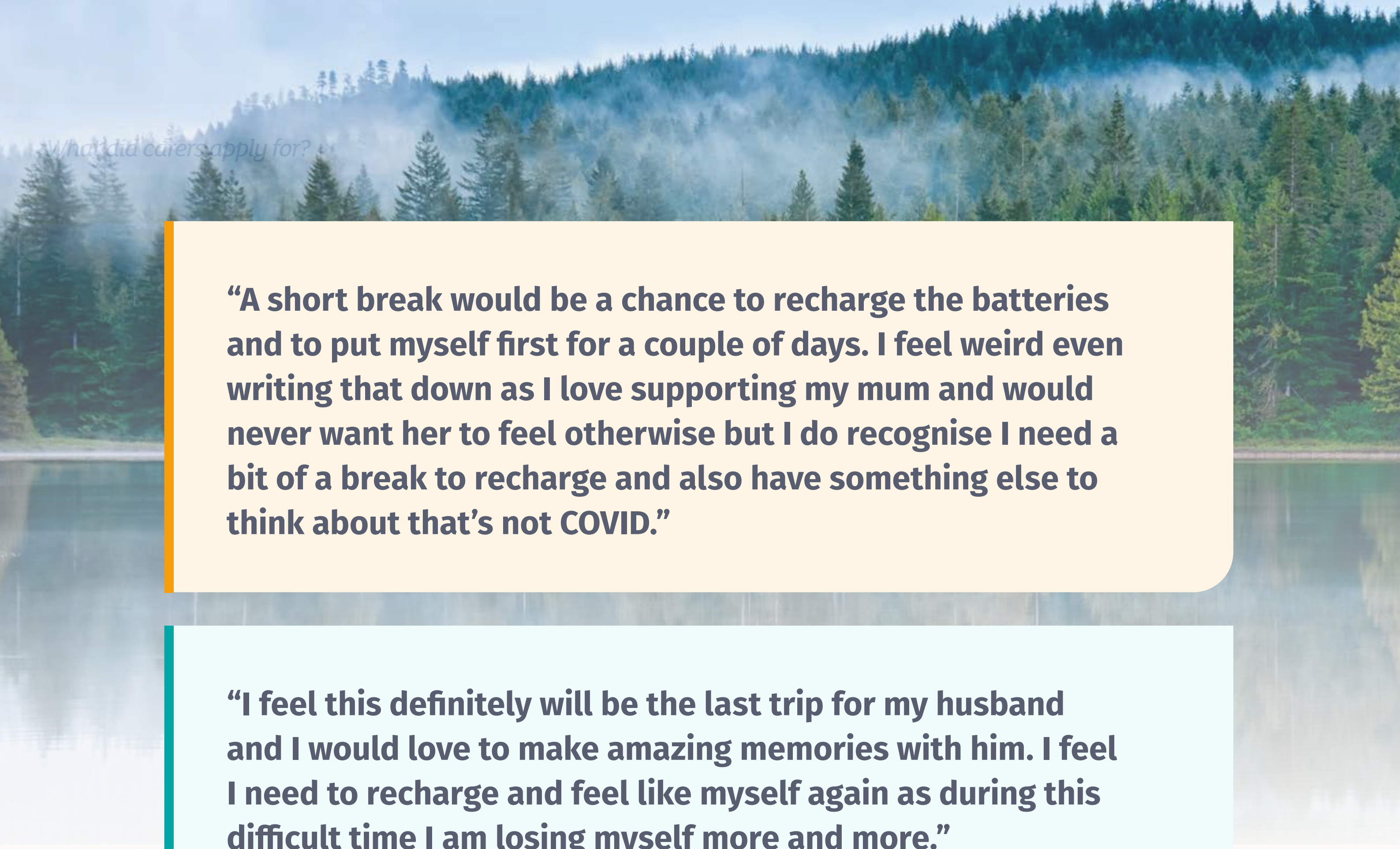
There were four requests for items relating to personal development or courses which would enable carers to gain new skills that would help them to re-enter the job market. They were an intensive driving lessons course; a journalism course; a course to gain a yoga teacher licence (all from people in the 45-59 age category) and study supplies (from a person in the 18-29 category).

> **"I used to work [in broadcast journalism] and miss writing – I would like to do a course on how to become a freelance journalist – perhaps writing at home. This would get me thinking and writing again and allow me an outlet of expression."**

Short breaks and respite care

There were 62 applications for support with a short break or respite care. The majority of requests for short breaks were to pay for travel and accommodation. Some carers looked forward to a stay in a hotel where they would get a break from domestic chores, whereas others preferred to go and visit family that they had not seen for a while. In some cases, the short break represented an opportunity to make memories with the person with dementia, possibly for the last time. It was evident from some applications that carers felt guilty asking for respite.

> **"I have carefully considered how best the Fund can support my wellbeing. I feel that a short break would provide the greatest benefit. It sounds selfish, but it would be nice to have a run of decent, undisturbed, beneficial sleeps; a cup of tea or a shower where I could relax without having to keep alert with one ear open or to enjoy a hot meal without being interrupted. I anticipate that a break will allow me to recharge my batteries as well as relaxing and enjoying myself for a short time. I'll also spend some time taking stock and consider Mum's likely future needs and how best to support her."**



> “A short break would be a chance to recharge the batteries and to put myself first for a couple of days. I feel weird even writing that down as I love supporting my mum and would never want her to feel otherwise but I do recognise I need a bit of a break to recharge and also have something else to think about that’s not COVID.”

> “I feel this definitely will be the last trip for my husband and I would love to make amazing memories with him. I feel I need to recharge and feel like myself again as during this difficult time I am losing myself more and more.”

Health and wellbeing

Forty-four requested items relating to health and wellbeing. The majority (15) were for massage sessions or other physical therapy but 14 asked for TV or magazine subscriptions, perhaps reflecting the increased need to stay at home due to restrictions on movement and closure of alternative activities.

> “I find that I can truly relax when I have a massage. It helps me to feel refreshed and revitalised afterwards and it lifts my spirits. I found it such a pleasure to have some time for myself and for me to totally ‘switch off’, even if only for a short time.”

Three carers asked for counselling sessions. One explained that counselling sessions would help her to manage the challenges of caring and provide somewhere to discuss details of her husband’s condition that she was unable to share with family or friends. All of these requests received funding.

Exercise and physical fitness

There were 80 applications relating to exercise equipment and gym membership. 14 applicants requested a treadmill, 10 asked for an exercise bike, seven asked for outdoor clothing and five requested a rowing machine. Other commonly requested items included outdoor bikes, cross trainers and gym membership.

> **"My daughter and I used to like to go out for walks together but can't anymore because with no support services or home-based respite available to us, one of us always has to be at home to care for my Mum. I think that if we were to purchase a treadmill this would benefit both our physical and mental health by letting us get our exercise without having to leave Mum or our house. I think that getting that regular exercise back into our lives again will help us feel better, improve our physical and mental health and give me more energy to help me cope day-to-day in my caring role."**

A carer who wanted to buy a bike explained the many benefits it would bring to her.

> *“This would support me in so many ways, for example it would enable me to be more active daily. I could make the time I spend cycling easily fit the free time I have available to me in between caring for mother. It would increase my health and metabolism and link in with my diabetes support plan. It’s important that I try to keep healthy as currently there is no one else to assist with my mother’s needs in my absence. It would also be another way to assist my weight loss. The cycle would enable me to enjoy time on my own or join in with a few others when they go out for cycling trips. The fact that it’s a free pastime for me is also very attractive due to my limited financial resources, as in this case the cost of taking part would not exclude me. Mentally it would give me a sense of freedom and for example I could easily nip to the local shops on it quickly. Even completing this application and thinking about the difference it would make for me has made me emotional.”*

One carer who applied for funding to purchase a new pair of walking boots and an outdoor jacket explained ***“Walking helps me clear my head and I can escape my husband’s mood swings due to his dementia. It’s so good for my mental health and physical wellbeing.”***

Carers views on the fund

Current circumstances

Between January and April 2021, the Trust received detailed feedback letters and emails from 82 carers. Each applicant had an opportunity to return a feedback form but not everyone chose to do this. Of those carers we received feedback from, the majority were either caring for their mother (35%) or their husband (40%) with 10% caring for their wife. Carers were also caring for their father, mother-in-law or a friend and in one case the carer was caring for both parents. Of the 82 carers who provided feedback, 16 agreed to be interviewed to provide further information about their current caring circumstances and the impact of the funding on their life. We spoke to them either by telephone or Zoom. We also received photos from some of the carers of the items they had purchased. These photographs have been used with permission throughout this report.

Reasons for applying

Carers found out about the Caring for the Carer Fund from various sources. Some had received information about the Fund from their Link Worker, whilst others had received emails from local carers organisations. Carers had also heard about the Fund from friends or neighbours who worked in health and social care or the voluntary sector and who were aware of the difficulties they were facing. Some carers were also told about the Fund via a local community project. It was encouraging that information about the Fund had reached carers through different organisations and demonstrates the importance of distributing information for carers through a variety of local sources.

> **“They [friends] suggested that if I want to keep on doing it [art] why don’t I ask if there’s any support available with that because they know that I do it to take myself out of worrying about my husband.”**

Often carers were hesitant to apply due to concerns that they were not eligible because they worked or were not full-time carers or because they considered themselves to be managing either financially or emotionally. Many had been encouraged to apply by friends, family or health and social care staff who were supporting them and the person with dementia.

Some carers may not have applied without this encouragement, feeling that the Fund was not appropriate for them or they were not 'needy' enough. One person's Link Worker had suggested that they might be interested in a poetry writing course. She was aware that the carer enjoyed writing and needed a few days away for some respite. The carer admitted that the course was **"way beyond anything she would normally allow herself to consider"** and the prompt from the Link Worker was key in supporting her to apply. Another carer was encouraged to apply by one of her friends.

> *"My initial reaction was, like, I don't want to take people's money, you know, I'm doing it because I'm doing it, so part of me didn't want to but part of me just felt like, oh it's really nice to be recognised for what we do. It was very mixed and I didn't apply for it straight away and I said to one of my friends, this is really great but I think there are people with greater needs than myself, I'm not going to apply for it and she said I think you should."*

> *"I feel very selfish asking for things for myself as I always put my mum's needs first, but I understand that is the whole point of 'Caring for the Carer', it's about the carer, it's about us and we need and deserve time too."*

Carers sometimes knew immediately what they would apply for. Often this was something practical and sometimes would also benefit the person they were caring for.

For those carers who were fortunate to have a garden, many mentioned how important this outdoor space had been for them during lockdown as a place to meet others safely. They were keen to use the funding to improve their garden or outdoor space so that it could be used more safely and effectively during the coming months.

> *"I find it relaxing, a space to sit and not be the granny, mum or carer. I find it really therapeutic, my own wee space in the world where nothing can intrude upon you. I can't imagine what it would be like to not have your own wee space, it is so precious. People who have a garden take it for granted."*

Another common reason for applying was to get a break from caring. One carer and his wife, who were caring for his mother, had experienced a brief respite when his mother was taken into hospital for a routine procedure. He realised that a night away in a hotel would be a good use of the funding and act as a thank you to his wife for her support with caring for his mother.

The opportunity to have respite funded was a lifeline for some carers who had been unable to get a good night's sleep for months.

> *"The one thing she needs is sleep. She cannot function properly and said her husband 'was only up four times last night.' Her husband has lost the ability to toilet himself and the outlook is not good. The local carers centre had a partnership with the pub across the road to deliver food, but food was not what she needed. Sleep was what she needed."*

Carers who recognised the benefits of exercise but were finding it difficult to fit it in around their caring role were eager to purchase something that would make this easier. One carer who had taken up running two years before applied for funding to purchase new running trainers.

> **"It's the best escape you can get if you have had a hard day at work and it helps with forgetting it all, clears your head but I can also think through a lot. Dealing with mum's situation and her emotions, I get quite down about it."**

Another carer thought very carefully about what to apply for because she wanted to get something that would benefit the whole family. She felt that her family had been really supportive in helping her to care for her mother so she applied for some gym equipment.

> **“And also the fact that the rest of the family can benefit from that because they have been cooped up. They’ve really enjoyed using the rowing machine and the exercise bike as well so I knew it was something that we could all benefit from. Temporarily during lockdown we’ve got them all lined up in the living room so we all just sit there together and take it in turns while watching the telly. We kind of encourage each other as well.”**

Carers were often keen to start or pick up hobbies that had been given up as a result of the demands of caring. One carer, whose mother was a very talented piano player, had given up piano when she was a teenager and had always meant to take it up again. She felt that this was a good opportunity to buy a piano and it would be something enjoyable that she and her mother could do together, which would bring benefits to them both. It would also bring back a lot of memories for her mum.

The flexibility of the funding programme enabled carers to change their request where appropriate. One carer originally applied for a new MacBook because the one she had was outdated and slow. She used it a lot to do internet banking and shopping for her parents. After successfully applying for funding, she took the old MacBook to the Apple shop to exchange it. The shop assistant’s grandfather had dementia and he offered to fix the laptop for no charge so that she could still use it for a couple of years. The carer decided to use the funding to do up her garden and to buy a printer so that she could print out signs for her parents to help them remember where things were in the house. She also used the printer to create menus for her mum who struggled to remember what to make with different meals.

Recognising that all carers have a different caring experience was key to supporting carers effectively. The funding approach appreciated that all carers have individual needs and that what helps one carer may not be the best support for another. Although there were some suggestions in the funding guidance about the type of things that carers might want to apply for, it was up to carers to think about what would support them best and this resulted in a variety of applications outside of the usual technology, garden furniture and exercise equipment.

For example, one carer wanted to buy a cashmere cardigan because she viewed it as a luxury that she would not buy for herself but that would make her feel good every time she wore it. There were also applications for TV subscriptions, a meditation and sleep app, a yoga course and driving lessons.

Caring for the Carer

Carers often described their caring role as a privilege and stressed that they did not expect or want anything in return for looking after someone they love. This made it difficult for some carers to accept that the Caring for the Carer Fund was to support them and not the person with dementia.

For many carers it was the first time that they had asked for help and, having managed without support for so long made it very difficult to do so now.

> **"I felt quite guilty actually. I felt guilty because I thought I've been able to do this without asking for help with it so should I be asking for help with it or should I not? And that was what the guilt was."**

Carers also reported feeling nervous or selfish about applying and often had mixed emotions of guilt and relief around asking for something for themselves. Sometimes carers were worried that if they received funding this meant that someone else would have to go without and directed the Trust to give the funding to those carers most in need if there was not enough funding for everyone who applied.

> **"It's not that we're skint, we're not in poverty or anything. I didn't get my pension, I get Carers Allowance so we're not in poverty at all and that was why I felt bad applying for the grant."**

Many carers admitted that they always feel that they have to save money for a rainy day and find it difficult to even think about spending money on luxuries for themselves.

> **“I know it might sound strange, but I can never justify to myself spending this kind of money on myself. If I know someone else has seen the merit in this kind of activity I will feel obliged to finally put myself first and look after myself better.”**

One carer who applied for funding for an outdoor pool table reported that he felt embarrassed asking for something that most would consider a luxury as it was not something that he would deem to be an essential item. However, he went on to write about what a wonderful escape it would be for him to be able to ***“hit some balls within earshot of mum’s living room”.***

This reluctance to put themselves first and the tendency to feel guilty for thinking about their needs is summed up in one carer’s response in her feedback letter.

> **“If the purpose of the Fund is to assist the carer then I have to ask for funds for myself. I would in many ways prefer to ask for funds to give to charity but I realise that’s not the point. I suppose I know that I won’t spend anything on myself because I’m not earning and I have to be sensible. So, if the fund wishes to make me as a carer cope better with this time in my life and hopefully by being happier be better at looking after my mum then maybe I need to ask you to fund something I would not buy.”**

Applications often revealed that the funding was viewed by some carers as a catalyst to start thinking about themselves and looking after themselves before they ‘burned out’.

> **“It made me stop to think ‘what about me?’ I actually couldn’t think what could make a difference, what would benefit me. It makes you stop and think about yourself which we don’t allow ourselves to do as carers.”**

The benefit of the funding went beyond the item for one carer who purchased an arbour seat for her garden, as she was given the opportunity to spend money on herself without worrying about it.

> **“It allowed me to buy for myself something I always wanted but put others’ need first. It was a wonderful feeling to be able to say ‘I have the money to get exactly what I want’. I can enjoy sitting in a sheltered spot, in comfort and relax, watching nature or reading. It is giving me great pleasure. The feeling of no guilt because it was money given to me. I never realised until now the light feeling that gave.”**

Others saw the funding as a welcome surprise and a boost during a challenging time. Carers described the Fund as bringing ‘a bit of hope for the future’ and ‘a ray of light in dark times’ and ‘a real treat’. One carer compared it to winning the lottery. Some carers commented that just the process of applying for funding was enough to generate much needed positive feelings.

> **“My wellbeing seems to be at zero just now and I have not thought about art until now, and this is making me feel good inside, even smiling whilst saying this to you.”**

> **“It has been a difficult year for us. My husband was one of the people who fell through the cracks for support after having worked for forty years. We had 14 weeks of no financial support and I only work part-time so it was a horrible time. We were offered a foodbank, that was it. When you discover that a charity is doing something like this, it just boosted us. It was extra special when you felt so low that someone else was offering to help.”**

Many carers commented that just the process of applying for funding brought a feeling of acknowledgement and of being listened to.

> *“I don’t normally fill in forms like this and, reading what I wrote above, I think I’m filling it in just to make myself feel I’ve told someone about what I am doing. I want someone to know. I guess I’m just glad to be communicating outside the house and that in itself probably has a value. I realise that I feel sad now about what I have written – it makes me feel like I should be doing so much more – but that will pass and I will be glad to have reached out I hope.”*

> *“A huge thank you for running the fund, the organisation and for the detailed follow up. I think that’s fabulous as well, it makes you feel like you’ve not just applied into a vacuum. It’s good for accountability it just makes you feel like you’re being listened to.”*

Feeling acknowledged and valued

One of the most significant outcomes of the Caring for the Carer Fund was that carers felt acknowledged and recognised for the difficult and demanding role that they do. Carers finally felt that someone was listening, that they were no longer overlooked, unappreciated and that they had not been forgotten. Time and again carers commented that it was not just the money that was important but the fact that there were kind and compassionate people who were thinking about carers.

It was important for carers to know that there was some understanding and recognition of the challenges that they face day after day and to have their often ‘invisible’ work acknowledged in some way. The funding made carers feel valued and special and provided a much-needed boost during the pandemic. Many carers felt that no one cared about them and the funding made them feel that they had been seen for the first time.

> **“I was really taken aback. I thought it was fantastic. I feel like I have become a bit lost in the whole process, the pressure of caring, no one thinks about you. It’s really lovely to have someone think about you.”**

> **“I thought it was lovely, a real boost for carers. It made you feel valued for what you’re doing, not that that’s why you do it. I felt like I was being listened to. It’s not just beneficial to me. It was a lovely surprise, gave you the real feel-good factor, made you feel really valued and that you’re being thought of.”**

> **“I think unpaid carers are generally forgotten about. To be given a token of appreciation has meant so much to me, as it proves that someone, somewhere is thinking about us and at least I am still on somebody’s radar.”**

Carers often feel they do not have a voice and many do not feel like equal care partners when it comes to making important decisions for the person they are caring for. The advantage of small grants is that carers can take control of deciding what they need to support them. This ownership was an important element of the Fund and helps to makes carers feel listened to.

> *"I just thought it was lovely that someone was actually asking me what I need rather than telling me what I need. I was so pleased that a form was asking "What do you need?" I couldn't believe it was successful. I got quite tearful because I thought someone is actually listening to me. It was a great initiative, a breath of fresh air. They asked me what would help. A magic wand would help. Respite is not sexy, new or innovative but it was what I needed."*

> *"I must confess on hearing I had made a successful application I felt tearful. Life has been tough this last year, I have not always felt supported and there have not been many successes to celebrate, but this felt that at least someone was listening - so thank you."*

What would have happened without the funding?

Two thirds of carers who responded[20] would not have bought the item without the funding. Some of the reasons for this were financial or practical but some were emotional. Many of the carers we spoke to were surprised and delighted to be awarded funding, with one carer comparing it to ***"a wee lottery win".*** Carers talked about the need to keep money for emergencies and to think about the future and keep money for other things. They felt that they would not have been able to justify the cost of buying certain items. For this reason, they would be inclined not to spend money on themselves, regarding this as ***"too self-indulgent"*** and viewed the items purchased as a luxury.

> *"No I wouldn't. I've got wee tubs of paint but they are not very big and don't give good coverage but the pens, I wouldn't have gone for all those colours, I just know they are so expensive I wouldn't even have looked. But because I knew this Fund was for me for my hobby I had great pleasure in looking to see where I could get them and what I could get. I wouldn't have had all these if it hadn't been for your funding."*

---

[20] One person did not respond to this question

> **“No, I would have sold my clubs. I wouldn’t have been able to carry on.”**

> **“No because I needed other money to tidy up the rest of the garden. I would have just grown flowers in pots. I also need to think about the future and keeping money for home nursing. The shed is a luxury and I’m proud of it.”**

A third of carers who responded[21] said that they would have got the item anyway or may have got it at some point in the future but suggested that they would have managed with an alternative, less expensive option or would have made the purchase later on when finances were in better shape.

> **“Yes but I would not have got it done professionally, it would have been a small job and not as good. I would not have had enough to get the uneven slabs done.”**

> **“I don’t know. I would have explored day respite but I wouldn’t have thought about getting carers in, especially overnight, as it is a very expensive option.”**

---

[21] One person did not respond to this question

Impact of the fund

The aim of the Caring for the Carer Fund was to support the wellbeing of unpaid carers during the pandemic, focussing particularly on:

- Coping with social distancing and isolation.
- Improving/maintaining physical wellbeing and health.
- Improving/maintaining mental health.

Analysis of the 82 guided letters that were returned to the Trust shows that a third of those who returned feedback were applying for support with all three outcomes. Just over half applied for support with coping with social distancing and 87% applied for support with improving mental health. Recognising the lack of opportunities for physical exercise during the first lockdown, 73% applied for an item that would improve their physical health at home.

Information about the impact of the funding was drawn from letters and emails received by the Trust, as well as interviews with carers. Where carers had been unable to spend the funding yet due to restrictions related to the pandemic, feedback was related to the benefits that carers expected to experience once they had made a purchase.

Coping with social distancing and isolation

Technology

We described earlier the impact on carers of having to socially distance from family and friends during lockdown and requests for devices to enable carers to become or stay connected to others were common.

It was clear from the feedback received that laptops, home computers and iPads made it easier for carers to take part in online activities, hobbies and fitness classes which provided external stimulus and a source of relaxation. Technology helped to maintain a connection to the outside world through reading the news and keeping in touch with family and friends. Importantly, carers were able to participate in online carers support groups which provided access to vital peer support.

A carer who had applied for funding for a new iPad to replace one that he had been using for eight years wanted to use it to see his sons regularly and access websites with activities that he could do with his wife.

> *"I understand there are Zoom groups run by the Carers Centre, and include training such as internet security, Coffee and Chat groups, and these things could be considered as well. I think this would really help my wellbeing as my wife and I used to be more active. With age and her dementia we haven't been able to get out very much at all and I would like to connect with local supports for both myself and the two of us."*

This carer intended to get some support from his granddaughter to set up the new iPad and was also aware that he could access a team of 'Digital Champions' through his carers' support worker if needed. Another carer felt that a laptop would help to compensate for the closure of support services used by his wife.

> *"Since the COVID pandemic hit us my wife's day centre provided by Alzheimer Scotland closed, the only interaction she and I have with the day centre is through various online "meetings" which are very helpful socially and informatively but my current laptop is slow and showing its age and needed replacing. The new laptop will assist me in keeping both of us stimulated and connected, by keeping my wife motivated and spirits positive this will be of benefit to my overall mental health and wellbeing. It will also help me keep in touch with my friends through social media."*

Applications for technology were important for other reasons. Many carers used technology to support them to access information about dementia which helped them in their caring role. It also facilitated attendance at virtual clinical or hospital appointments, keeping carers in touch with health and social care professionals who were also a source of support at this difficult time.

Technology was also useful for practical tasks such as internet banking, food shopping, re-ordering prescriptions and for de-stressing by providing access to meditation websites and apps and online exercise classes.

> **“I will make such good use of a new laptop. I order a lot of things for my parents via websites such as their frozen meals, medical supplies etc. I also keep in touch with my children via internet and we have group family calls which my parents enjoy joining in with and the laptop will allow us to see everyone well. I also do internet banking etc. and find it a bit tricky on my phone so this will be easier on a laptop. My current laptop is so slow that it takes me ages to do anything on it and time is something I do not have a lot of.”**

> **“We can Facetime the grandchildren again when we don’t see them. It helps my wife as she sometimes forgets the last time she saw them and of course she can play online games again. My wife is soon to go into the hospital as well... which is obviously worrying due to her Alzheimer’s and maybe not getting visitors so now we will be able to ensure she has the iPad with her so we can keep in touch.”**

A carer who had given up her own business to care for her mother applied for funding for a laptop. She had really loved her job and missed being able to go out to work which was having a detrimental effect on her mental and physical health. She did not have any time to herself, and was feeling exhausted most of the time. She had limited access to technology and the internet using her phone. As well as allowing her to keep up with friends and family and access information the new laptop would also support her to get back to work. A friend had suggested creating a website for her, so that she could look at restarting her business.

Technology also provided respite for carers. One gentleman requested an iPod and headphones so that he could listen to music and relax while his wife watched her soaps on TV in the evenings.

> **“...now I can sit in with her as she watches the TV and enjoy the music that I like on iPod with headphones and we are still together in the same room plus will listen as I go about my daily life looking after her and with the music I choose will give me another interest and at times when feeling down just put the music on, this is going to be a great gift from your fund.”**

Maintaining connections through technology

Francesca's Story

Francesca's mother received a diagnosis of early onset dementia just before lockdown. Because social work services were being delivered remotely, there were many delays in getting the support that her mother required. Although Francesca managed to access a Dementia Link Worker, they were unable to visit her mother in her home throughout 2020. Her mother was unable to access any of the groups that Francesca had organised for her and she had been awaiting an OT assessment for her stairs since the beginning of lockdown.

Francesca was trying to monitor any changes in her mother's health remotely in addition to organising social work assessments, professional carers, medical appointments, shopping, cleaning, bills and medication. Knowing that her mother was lonely was adding to Francesca's stress.

> ***"Basically I feel like my Mum and I have been holding our breath, waiting for this to come to an end and there is no end in sight."***

Due to her eye condition, Francesca's mother was no longer able to read, operate the radio or knit. Francesca had noticed that using the phone was becoming difficult and frustrating for her mother and she was concerned that she would start to avoid using it. Francesca applied for funding for an Echo Show, a device that has a microphone and a camera, so that she could speak to and visually drop in on her mother, who has dementia and macular degeneration, at any time. Francesca felt that her mum would also be able to use the Echo Show to listen to the radio, podcasts and audible books, keep up to date with the news, call her friends and family and check the date, time and weather.

"For nearly a year, I have tried to keep my mother motivated, engaged, but I can't hold my breath any longer. I know that my visits give my Mum new life and I also know that the interminable loneliness and the lack of things to do, is slowly demotivating/killing my mother. The longer this goes on the more stressful it becomes and the more desperate I feel. So to have access to these aids would be like throwing us a lifeline."

Francesca's mother had absolutely no experience with any form of modern technology but the Echo Show is voice / touch activated and allows the user to make phone calls, switch on their TV and it can also be linked to put on heating and lighting. It also has sensor motion equipment.

"The Echo Show has helped address my Mum's isolation/ loneliness. She calls us regularly, listens to music constantly and has taken to asking it all sorts of questions. Being able to "see" as well as speak to my Mum, has been a godsend for myself and the rest of my family... Her eyes literally light up at being able to see us during phone calls. So much more meaning to our interactions. It is like being in the same room, truly revolutionary! Even so, now that we have it in place, we can help Mum with any difficulties much more easily, now that she can see and hear us."

Francesca described the difference that the device has made to her and her family as transformational.

"This has all been truly life changing for my Mum and us, her family."

Francesca told us that her mother is ***"much more engaged in conversation, whereas on the phone, she was always trying to read from her little notes and would get very distracted and then end up saying "I'm fine" to everything, even though she wasn't."***

Francesca created prompt cards to help her mother remember different commands for the device and to personalise her favourite radio stations and singers. One of the most useful features which has helped Francesca with her caring role is the 'drop in' facility which she uses to check that her mother is alright, which has provided peace of mind and allows Francesca to see if her mother is 'up and dressed', prompt her medication and drinks and remind her about appointments.

> ***"It has reduced the stress of not knowing what was going on, or how my Mum was really feeling, feeling so helpless, plus it allows me to connect directly with her carers/ visitors too."***

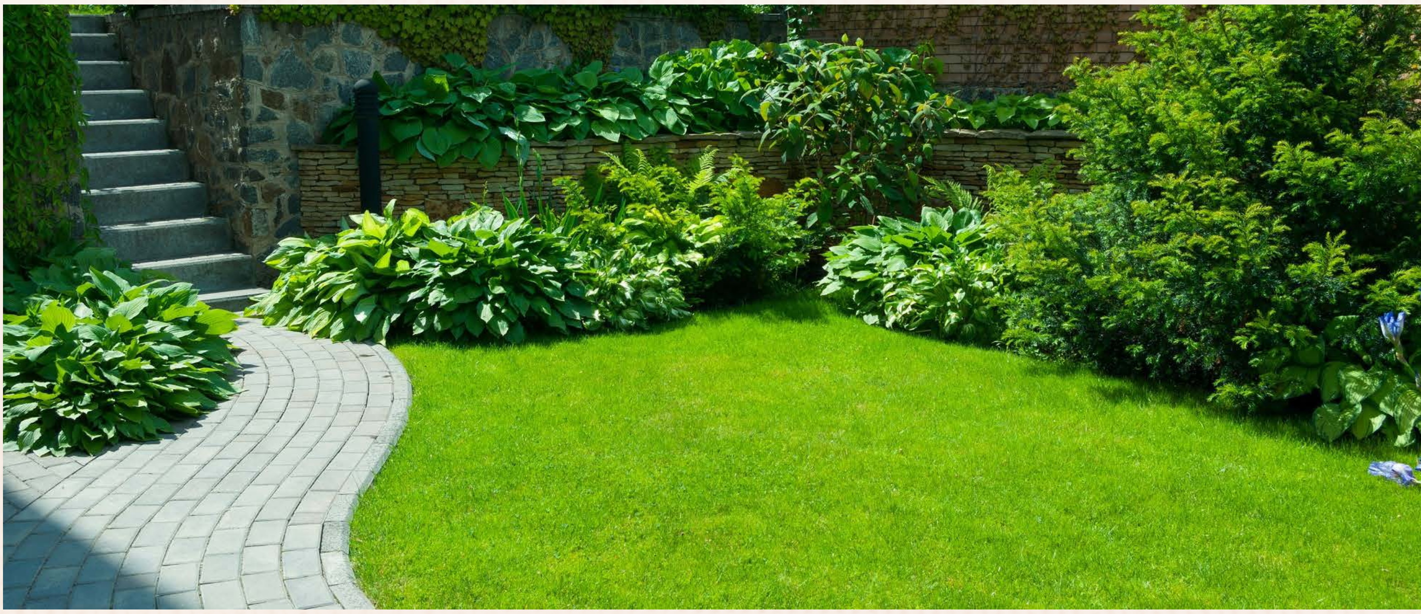
Garden improvements and furniture

The importance of outdoor spaces in helping to maintain connections and reduce social isolation really came to the fore during the pandemic. Those fortunate enough to have a garden wanted to use funding to improve this space to encourage visitors and create a comfortable space to relax and meet with family and friends in a safe environment.

After nine months of not having visitors to her house or being able to meet friends elsewhere due to worries about her mother catching COVID, one carer received funding to create a safe external meeting area. This provided her with a place to see friends safely and enabled her mother to have more meaningful interactions with family, reducing the carer's worries about her mother being isolated. This in turn had a significant impact on her mental health and wellbeing.

> **"[The gazebo and heaters] gave me the opportunity to have at least an element of social life and relief from the caring role, out in the fresh air in all weathers and out of the house which is important… so important to take time out and relieve the stresses."**

Not being able to travel or go anywhere for a break made these outdoors spaces all the more important. One carer whose mother was unable to manage being out all day for a day trip wanted to improve her garden so that she could provide a change of scenery where they could visit safely.



> *"It will be a huge weight off my mind. My parents can come and visit and have a happier time. I would spend more time in my garden. It would make me feel better. I can't invite friends round at the moment."*

In some cases, restrictions during lockdown meant that carers had to wait to get work carried out but some, like this carer who received funding to repair the stairs accessing her garden, told us about the benefits they expected to experience.

> *"...because of the restrictions we haven't got the stairs done yet. But we have had the path edged and I'm looking forward to the garden being finished. It will enable me to spend time in the garden safely. The garden has been a place, particularly during the COVID restrictions of movement, where I can relax and have time for myself. The garden offers me a space to exercise and clarify my thoughts and responsibilities. I can't go anywhere and I joke that I'm going to go on my holidays in the garden in a tent. It will be good to walk up and down to the garden without a hard hat on."*

Improving / maintaining physical wellbeing and health

It was clear from speaking to carers who had applied for exercise equipment that they had experienced real benefits in their physical health. Since there is a close link between physical and mental health and wellbeing, many carers had also seen an improvement in their mental health.

During lockdown everyone was encouraged to go for regular walks but some carers were unable to manage this due to mobility issues in the person they were caring for. There were lots of requests for gym equipment and home exercise machines which could be easily stored and allowed carers to access physical exercise in the confines of their own home, whilst keeping an eye on the person they were caring for. This provided many carers with reassurance that they could be within earshot of the person with dementia, while also getting a short break to exercise.

Having gym equipment in the home also meant that carers could fit exercise around their caring responsibilities and no longer felt that they had to ‘clock watch’ in order to be back within a certain amount of time to check on the person they were caring for.

> **“I applied for funds to buy a treadmill. It was helpful to me as I am unable to go out to exercise, even for a walk as I need to take my Father with me when I go out and he can only walk very slowly and very short distances. It really mattered as I really feel it’s important for my physical and mental health to be able to exercise and with the treadmill I can use it at home after my Father has gone to bed.”**

> **“When I use the rowing machine and exercise bike rather than going out on my bike around the roads I just feel like I don’t need to look at my clock so much and I’m a bit more relaxed that dad can get hold of me if he needs me.”**

Carers recognised the impact of physical exercise on their mental health and were often using physical exercise to manage their own anxiety and stress, so it was important to be able to continue this with the help of the funding. A successful application for a new bike and cycling shoes gave one carer the opportunity to continue her love of cycling. She described how important this was in helping her to cope with her responsibilities as a carer.

> *"I have had some real down times during my period as an unpaid carer. It goes without saying that my mental health has been helped due to the improvement in my physical health, increased confidence and forming friendships with people I can trust and share with. [Receiving funding] was fantastic news as it will allow me to continue to maintain my wellbeing, stay connected in this time of social isolation as cycling is one of the things we can do and even in full lockdown we can meet up with one other and to stay physically and mentally well. This has helped me to cope as a carer and stay strong to look after my mum."*

Receiving funding to purchase an electric golf caddy to help him carry his clubs around the course enabled one gentleman to continue playing golf. This was important to him as he had given up golf because of back problems and it was a way for him to recharge his batteries. The caddy meant that he was able to continue playing and enjoying golf which improved his physical and mental health.

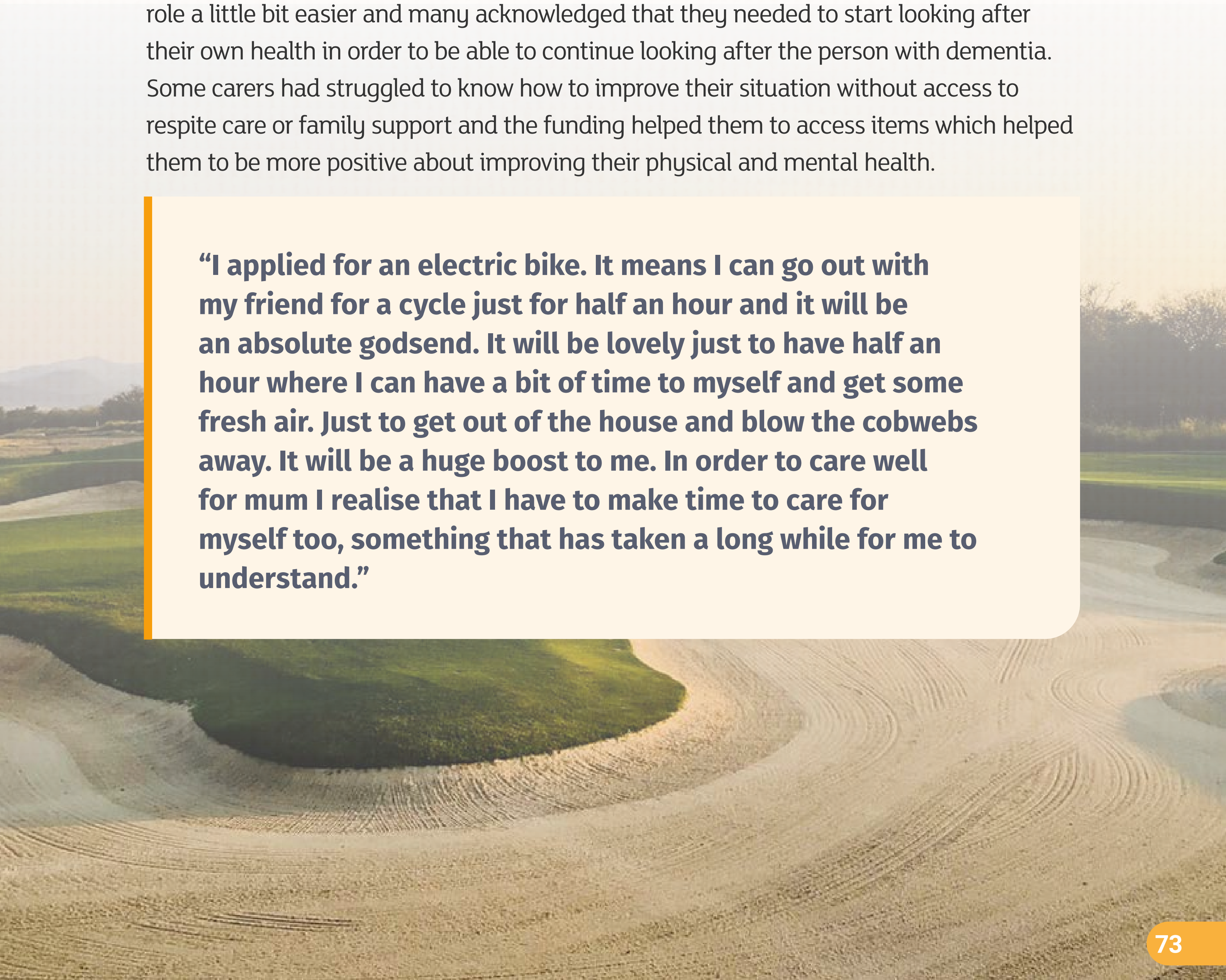
> *"I have sciatica and I was still playing golf ok but I struggled to get the clubs round the course and it was getting me down. It has been brilliant. To start with I was playing 11 golf holes, three times what I was playing, and now I am playing 18 holes again. My anxiety has dropped, I'm a lot calmer. The change in my life has been unbelievable just because of this one thing. It has made a difference to my wife, it helps her. She knows I need to get out, to stress less. Playing golf for one hour a week is absolutely pure bliss."*

Funding for golf club membership allowed one carer, whose husband had early onset dementia, to get a regular weekly break for a few hours to step away from her multiple roles as housekeeper, breadwinner, gardener, driver, parent and decision-maker. The club membership enabled her to get some respite and physical exercise which boosted her wellbeing and let her relax for a while.

> **“...that time on the golf course allows me to be just a very amateur golfer. I get a real buzz after a round of golf in the fresh air, it is hard to explain. It gives me somewhere to go where I can exercise and keep fit, but it’s also a place where I can go to relax and just forget about all the stresses involved with caring, even for a short time, before it all starts again. Getting away for a round of golf with a friend is so enjoyable and a chance to get away from my worries and fears.”**

Carers found that physical exercise helped them to sleep better, which made their caring role a little bit easier and many acknowledged that they needed to start looking after their own health in order to be able to continue looking after the person with dementia. Some carers had struggled to know how to improve their situation without access to respite care or family support and the funding helped them to access items which helped them to be more positive about improving their physical and mental health.

> **“I applied for an electric bike. It means I can go out with my friend for a cycle just for half an hour and it will be an absolute godsend. It will be lovely just to have half an hour where I can have a bit of time to myself and get some fresh air. Just to get out of the house and blow the cobwebs away. It will be a huge boost to me. In order to care well for mum I realise that I have to make time to care for myself too, something that has taken a long while for me to understand.”**



Applications for practical items also helped to relieve physical ailments experienced by carers, ultimately helping them in their caring role. For one man who was suffering from lack of sleep caused by sleeping on a sofa, using the funding to buy a sofa bed helped to improve his quality of life.

> *"I have been suffering from back problems associated with my sleeping position on the existing sofa. I will now enjoy a decent sleep and my overall health will improve. I could not afford to replace the sofa. Obtaining this grant is the best thing that's happened to me in the last year and has given me a much better view of coping through the lockdown."*

The flexibility of the funding was key to helping a carer address a health problem which was making her feel ill and adversely affecting her mood. She had received funding for massages but then discovered that she was suffering from vertigo. She was unable to get a physiotherapy appointment through the NHS and was able to use her funding to access a private physiotherapist instead. This meant that her vertigo improved more quickly, which enabled her to cope better with her caring role.

> *"I've still got the funds there to have another session and I'd rather do that than have a massage just now until I feel safe. That has been a great help to me because I was getting really nauseous and bad tempered, and quite depressed actually, because that's four weeks I've had it. I really was quite depressed about it but it feels better now that this is going away and I'm more able to cope. If I hadn't had the funds there I wouldn't have even thought about it. I would have thought should I do this?"*

Applications for health treatments, such as massages, were common with carers recognising the benefits in reducing tension, pain and stress levels, enabling them to return to their caring role refreshed and with more energy to care. The cost of these treatments can be expensive and some carers used the funding to build in regular sessions that would help them manage long-term.

> "I feel these massage sessions will be particularly helpful because my shoulders, arms and back are painful quite a lot of the time, due primarily to the assistance I give to my husband re getting out of a chair and in and out of bed. To be able to have a couple of massages a month, I think will help to ease the pain and allow me to relax."

> "Caring for my wife who has dementia leaves me quite tense at the end of the day – and often during it. An hour at the hands of a qualified masseuse gives much relief which lasts for several days. Tension and pain can result in me being irritable and short tempered which I try to hide but it does surface and is unfair to my wife. The reduction of pain also enables me to enjoy other activities such as gardening and baking."

Improving physical and mental health

Jack's story

Jack is in his early fifties and, along with his wife, cares for his disabled daughter and his mother, who has dementia. He also has a health condition which causes pain in his neck and back and feels that this has been exacerbated as a result of his caring responsibilities.

> ***"COVID has had a huge impact on my life, all respite stopped along with day services, leaving me with no support. For my mental health I took up an old hobby of cycling which meant I could social distance, keeping my family safe from COVID while giving my mental health a boost and physically it's not hurting my joints."***

Jack told us that he needed a bike with better gears for the hills where he lived but he would never have been able to afford this type of mountain bike.

> ***"A mountain bike with a lighter frame and better suspension will help me get out and about in the local woodland paths and hill climbs. Cycling is good for my stress and I feel it relieves my back and muscle pains. I can't do any other sport due to my health condition. My mental health is better after I have been out on the bike."***

He applied for a mountain bike which he described as a ***"life changing gift"***.

> ***"This mountain bike was the perfect bike to get round the woodland paths and up to where I live. The paths can be very rugged and the suspension helps. This was the perfect fit for me. [The bike manufacturer] only make a few M/L frame size and I got the last one in Scotland. I never apply for anything and think this only happens to others. It's my turn now, what a feeling."***

Improving physical and mental wellbeing and health

Sarah's Story

Sarah is in her sixties and lives with her husband who is disabled and has mixed dementia. Sarah also has health conditions and suffers from anxiety. Sarah's husband used to go out for two hours every week with a paid carer, however this stopped when the pandemic started, due to restrictions on car sharing. Sarah and her husband were also nervous about allowing anyone into their home because of the virus, so they were not keen to continue with this support. Sarah's husband participates in a Zoom brain gym group once a week for an hour. This is the only support they received. Unfortunately, family were unable to help because they are key workers and their jobs made it too risky. The couple felt trapped in their home.

> ***"We used to like to go out for lunch maybe once a week to the garden centre or a stroll to the big park with the dogs but we've been too afraid to go to the big park because it's too busy, especially while the children were about because they weren't at school. We've not been out much at all."***

Sarah felt quite guilty applying for the funding because she had been able to manage up until then. She heard about the funding through the e-newsletter from her local carers centre and decided to check her eligibility.

> ***"I went to the website to look at everything that you did, I was trying to see if I would be eligible in terms of financially or my caring situation but I couldn't find anything that said I wasn't so I thought, well what have I got to lose, I'll just try anyway."***

Sarah successfully applied for materials to continue with her hobby of painting.

> ***"I like to do anything creative. One of my favourite pastimes is painting which I usually try to do in the evening while my husband watches TV, nearby."***

> ***"I find when I'm concentrating on painting I'm so focussed because the work is tiny, I'm so focussed on it that I don't think about other things when I'm doing it and I know I just need to lift my head and I can see that my husband is fine and I'll carry on. You close out everything else and concentrate on what you're doing when you're being creative. It's a great respite I find for me."***

Sarah also had problems with her neck and shoulders and prior to COVID she tried to have a relaxing massage as often as she could to ease the stress. But the cost was sometimes an obstacle. She decided to apply for funding for a monthly massage for one year.

> ***"It was lovely and it really made me feel good. It sounds silly but I felt more patient with my husband after that and it must have been because I was relaxed. But I did find it such a benefit. So, this payment, which I will keep in a separate account, will allow me to enjoy that relaxation every month, bliss!"***

As well as improvements to her physical health, Sarah also expected benefits to her mental health, in particular reducing her anxiety.

> ***"This payment will allow me to continue to paint for the foreseeable future. It gives a pattern to my week, provides a focus away from caring and gives me confidence in being able to create something. It is very important to me to maintain good mental health, to avoid increasing stress levels and my own wellbeing, and in order to continue to care for my husband at home for as long as I can. I am very grateful for this funding so that I can continue to care for my husband while maintaining a little bit of space and time for myself without the worry of funding the activities I can enjoy."***

Improving / maintaining mental health

Although there were clear links between physical health and mental health, carers also requested funding for items that they felt would benefit them in reducing stress and improving their mental and emotional health and wellbeing.

For many carers, their gardens or outdoor spaces were not just important in keeping them connected to others, but being outside was also important in helping to restore them. A carer whose family had struggled financially during the lockdown after missing out on financial support, requested funding for garden improvements. The garden helped to alleviate the stress caused through sudden loss of employment and provided a place to relax and come to terms with her mother's dementia diagnosis.

> *"I can't tell you how much difference it has made. I can sit and look at the garden from my living room on a wet day and I can't imagine not having it, it's an extra room bringing the outside in. It's a place I can go that makes me feel calm. When my mum was diagnosed I was resentful and couldn't handle it well… I really struggled and I ended up on anti-depressants. If I didn't have the garden I would have nowhere to direct that bad energy to, it's a release. I can sit out there and close my eyes and I could be anywhere. It's peaceful."*

One carer found that her new potting shed allowed her and her mother to spend time together outside which made it easier to communicate with each other. Her mother was able to sit in a shelter while she potted up plants. The benefits had also extended to the rest of the family.

> *"It's helping to get us working as a family. Improving my relationship with my husband. We've had years of being very isolated even though all in the same house. We'll all be in different rooms doing different things. It's like we're all lodgers. Being comfortable outdoors is pulling us back together. Things feel easier and less stressful outside so it's good for mental health."*

Many carers applied for items for themselves but which would also make their caring role a little bit easier, which subsequently helped to improve their mental health by reducing stress. Sometimes the funding was for something which the person with dementia could get involved in too, an activity they could safely do alongside the carer. In the absence of external activities and events this provided some respite for the carer. One carer who applied for raised beds, compost and a bench discussed the benefits for her and her mother of applying for garden items.

> *"I am finding there are fewer and fewer things we can do together that does not involve outside assistance or a lot of planning on my part. Pottering in the garden offers a safe activity which makes her feel useful. I can talk to mum about what to grow and it stimulates her which takes pressure off me to find stimulating activities for her. I thought it would benefit mum as well as me. It was to do with her but not totally centred on her. I feel guilty if I leave her on her own. This way it is something for me but she is also close by. It's also reassuring for me. It is relaxing and it takes my mind off caring. It's mindfulness really. I can see that mum is ok without having to check on her all the time. It also gives me a haven to go to if I need a break or 'time out' without having to leave the house or get in alternative help."*

Many of the feedback letters and emails mentioned how the funding had helped to make life a bit easier for carers because it enabled the carer to get on with doing something enjoyable and meaningful to them whilst also providing peace of mind for them and reassurance for the person they care for.

> *"I can sit at the table in the dining room and I can see what he's doing and I can paint at the same time. It's ideal because it means I am having time to do what I want to do but I can see him at the same time. He can see me so he knows where I am and he can see what I'm doing. It lets me recharge my batteries while I'm doing that and makes me less impatient with him."*

Creative pursuits and hobbies were also popular. Carers used creative activities to relax and forget about their worries for a short time and were often able to involve the person they were caring for in these activities, sharing experiences which helped to bring them together. Carers welcomed the opportunity to learn new skills and use a new challenge as a diversion from their caring responsibilities.

> **"It gave me an opportunity to do something for myself within my home and engage my brain in a fun, learning capacity. Playing the guitar temporarily took me out of the world I was living in and transferred me to another world where song lyrics replaced the run of the mill thoughts I experienced day-in-day-out. It was something I could also share with the person I cared for in a happy, productive environment."**

After using the funding to buy a Yamaha digital piano one carer, who shared a passion for music with her mother, wrote:

> **"It is already making a difference to our lives as it has given both Mum and I a renewed enthusiasm to rekindle our love of music and singing. It provides me with a form of escapism, time for me and an opportunity to progress. It is therapeutic and relaxing. It's nice to do something that you can get engrossed in and forget all your cares and troubles. It gives you a purpose. When you're caring, your time is very tied up and there is not much time to yourself. It gives you joy and makes you feel good inside."**

One carer had used art as a form of respite prior to COVID but caring full time for her mother meant that she no longer had time to set out equipment and materials and was unable to leave paint and paintings out undisturbed. Consequently, she was losing interest in art and found that her hobby was becoming more stressful and less enjoyable. She applied for funding for an iPad Pro and pencil to support an art app which would allow her the flexibility to fit art into her caring role and enable her to do it anywhere and at any time.

> *"The iPad as a standalone art package has been truly amazing. Its portability and ease of use has lowered the barriers to my own hobby, enabled me to clear space within the house and carry out my art in a comfortable setting. Now on a very neat machine I have the freedom to experiment with both drawing and painting at any time and in any location with little effort on my part, which has rekindled my interest and enthusiasm and brought colour back into my life. I assure you that the award has provided the respite and help I was badly needing as well as bringing back the enjoyment and fun of painting."*

A new sewing machine meant that one carer could make soft furnishings and decorative items, which made her feel calmer and helped to manage the stress of her caring role. She was looking forward to the sense of achievement that she would feel with the items she was going to make on the machine.

> *"I find sewing very absorbing and destressing, for me it is quite a mindful practice and I think it will help me to feel calmer. For me this is so positive, with all the stress and endless challenges, to have something tangible and creative to think about and plan, to shut this stuff down for a bit and get absorbed into some other activity will be really helpful. It will be wonderful to be able to achieve something too, to have some finished products that I have made, and having the machine will allow me to do so much more than I can achieve by hand. I am really looking forward to it."*

Having an opportunity to relax, even for a short time, was important to carers in reducing stress and restoring themselves to face the challenges of caring during a pandemic. A carer who asked for funding for garden improvements described the impact this had on her wellbeing.

> **“The garden is a sanctuary for me, especially last year when weather was good. My role as a carer has been a huge shock to me, and has taken about a year to adjust mentally. The space in my garden is precious, it is one wee space for me to be on my own, just to relax, put things in order again. Now I will be able to re-do the area. It is small but peaceful and even if the weather isn’t great, I can wrap up and ‘escape’. Part of dealing with the stress I have felt is the ability to have my own space and time, even for a few hours, or just minutes. To have a coffee – feel the sun on my face, breathe!”**

Improving mental health and reducing social isolation

Louise's Story

Louise is in her 70s and looks after her husband John who has vascular dementia. COVID means she can no longer meet her friends or attend her fitness classes. Her family is unable to visit and she feels like her normal life is on hold. She is unable to leave her husband for very long or go very far as they both have to isolate. Her husband had three falls in one month and cracked a rib. Louise feels very lonely and worries about supporting her husband. Her mental health has suffered, her stress levels have increased and she struggles to sleep at night. She feels tearful and her brain feels numb at times.

Louise applied for funding for an arbour seat and garden furniture to help support her wellbeing.

> ***"I can sit and read and relax in a sheltered area and get a break from the confines of the house. I love being in the garden but it can be cold and windy at times due to the weather. I believe having a shelter will help me to relax whilst at the same time being in hearing distance from my husband. To have a sheltered space to go to would help my wellbeing as I may be able to enjoy the peace and tranquility in my garden. Watching the birds and wildlife may offer me some assistance with helping my brain to unwind. Some garden furniture will mean that a friend or family member can meet outside whilst socially distancing from me and a chat would be most beneficial for my mental health."***

Although carers often found respite in their gardens or in participating in creative activities, it was difficult during the pandemic to access respite in the form of a short break. It is not, therefore, surprising that many of the applications asked for funding for a short break or to cover the cost of respite care to enable the carer to get some time away from caring. The funding provided many carers with the opportunity to take proper respite by either paying for accommodation and travel costs or to pay for someone to take over caring for a short time.

> *"I just want you to know how much I appreciate this. I love mum but I need a break. It's been a very difficult winter, mum in decline, miserable weather and finishing at work. This has given me a boost, one I was seriously needing. My mental health, not the best in the winter, has been declining but this has cheered me up no end. I know, not a big deal in the grand scheme of things, we are still alive, but they are coping mechanisms, stress relievers which no longer exist at the moment. I couldn't afford it on my own. It gives me something to look forward to. I will come back refreshed and recharged to carry on with mum."*

During lockdown carers were not able to book any respite due to travel restrictions but it was clear from feedback that the opportunity to plan a short break at some point in the future was enough to lift spirits and that the change of environment would provide a space for carers to 'recharge their batteries'. A carer who received funding for a short break to visit her family told us that she had applied largely to catch up on sleep. She recognised the importance of building in regular respite to support her to continue to care for her husband.

> *"I think this would help restore my energy levels and give me some valuable space and time to think about some other positive strategies that might help us going forward. Just the idea of going out somewhere, having someone cook my dinner for me and wash up. I will be rational, sane, it will restore me temporarily."*

Carers observed that they were able to relax on a break in a way that they were not able to at home. As one carer said, ***"I think because you have to surrender some control and accept you can only do what you can do."***

In recognition of the lack of available respite opportunities for unpaid carers during the pandemic, in January 2021 the Scottish Government announced an investment of £750,000[22] in local carers centres to increase support for unpaid carers. Carers centres were able to give small grants to carers to spend on something that would support them to get a break, such as leisure equipment, hobbies or entertainment subscriptions. The funding also aimed to enable carers centres to extend some of their existing services, such as befriending, counselling or online support groups.

Supporting carers in their caring role

Some carers used the funding for very practical items that would help with day to day caring or would enable them to take a break from responsibilities. One carer bought a mobility chair for her husband, while another used the funding to buy takeaways from a local hotel so that she could have a day off per week from cooking for a few months. A new printer enabled one carer to print signs for her parents to help them around the house, allowing them to live in their home for longer as independently as possible.

> *"As his sole carer, because I have been diagnosed with Rheumatoid Arthritis and am finding it impossible to raise him from his chair or sofa wherever he is sitting. This was the best thing that could help me right now and I cannot explain properly the difference it has made to both of our lives."*

> *"I am going to buy a printer and then I will be able to print out notices and signs for my parents as they are finding some things around the house challenging as they both have dementia."*

Carers were able to purchase expensive items, such as kitchen appliances, sooner than they would have been able to without the award, making everyday tasks a lot easier for this couple in their eighties.

---

[22] https://www.gov.scot/news/extra-funding-to-support-unpaid-carers/

> **"These items I have listed were old and needed replacing to make things easier in the kitchen. I was hoping to replace them in the near future when other funds were available. Now I've been able to buy them sooner than expected. Defrosting the freezer has been more difficult recently. The new toaster arrived today, perfect toast at last."**

Funding helped some carers who had found themselves taking on new tasks and responsibilities as part of their caring role. For example, a new laptop made it easier to print out information, access support online and handle household administration. Often the benefits of the item went beyond the carer and had an impact on the wider family as well as the person being cared for.

> **"When she [his wife] realised what it was her face lit up and she was so pleased for me to get something for myself. I buy myself nothing, I never treat myself. It's a personal gift for me… My daughter is happy – she has bought me some more golf stuff. It's like a tree that has grown and stretched out branches to everyone. From small acorns…"**

> **"It will also help my sister whose son is autistic, she can sit outside and relax. And my mum is in a wheelchair so the ramp will mean she can access the garden easily. It helps everyone. It helps visitors from the family, if they need to go into the house to use the bathroom they don't need to worry about falling."**

What did we learn about our funding approach?

Delivering a programme of small grants for unpaid carers

Learning from the Individual Awards Scheme[23] delivered in 2014-15 and 2018-19 demonstrated that "***a model of a small grant, issued through a simple, trusting and supportive application process, with flexibility to choose and change decisions on spend, allows people to have control and to make decisions that maximise the outcomes for themselves."*** The approach taken for the Caring for the Carer Fund built on this learning and conversations with projects delivering support to carers during the pandemic disclosed many of the challenges that carers were facing.

Broad eligibility criteria

It was important to ensure that the Caring for the Carer Fund was as accessible as possible to a wide range of carers. This was achieved through having a broad eligibility criteria that allowed carers to apply for anything that would support them with any of the outcomes that the Fund focussed on:

- Coping with social distancing and isolation.
- Improving / maintaining physical wellbeing and health.
- Improving / maintaining mental health.

Often unpaid carers were experiencing financial hardship and the broad eligibility criteria enabled them to use funding to purchase essential items. Evidence from applications to the Fund highlights the individual nature of each caring journey and the individual needs of each carer. Any response to the needs of unpaid carers must acknowledge this and provide the flexibility to focus on the outcomes of the carer rather than how this is achieved.

---

[23] https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning

> **“A person-centred approach would acknowledge that unpaid carers are not a homogenous group; we come from all ages, from different cultural and ethnic backgrounds, and with very different caring experiences. Each of us have our own needs, desires, and aspirations, and these cannot be addressed by a one-size-fits-all service.”**[24]

There is still a lot of work to be done engaging with Minority Ethnic communities around dementia, as demonstrated by the low numbers of applications from people who identified as non-white. Previous work carried out for the Trust[25] identified a number of barriers to engagement including language barriers, misperceptions, inaccurate translations, and lack of cultural awareness. Working with third party organisations who support unpaid carers from Minority Ethnic groups can increase the reach of funding and ensure that unpaid carers from diverse communities benefit from small grants.

Simple application process

The simplicity of the funding approach was important in helping as many time-pressed carers as possible. Carers had the option to submit their application by post or complete it over the phone with a member of staff if they were not comfortable completing it online. The application form and guidance were straightforward and in plain English. Feedback from carers showed that they valued the brevity of the form and the opportunity to describe their situation and what would improve their circumstances.

Involve carers in assessing applications

A decision panel comprising current and former unpaid carers brought deep knowledge and experience-based judgement to the process, much more than would be available with a traditional panel consisting of only funding staff. The guidance materials emphasised that applications would be assessed by current and former unpaid carers of people with dementia and their advice was particularly helpful to Trust staff when providing feedback to unsuccessful applicants. The flexibility of the decision-making process allowed the panel members and funding staff to incorporate learning as they went along to ensure that the process was constantly refined.

---

[24] https://www.gov.scot/publications/independent-review-adult-social-care-scotland/ Shubhanna Hussain-Ahmed

[25] https://www.lifechangestrust.org.uk/publications/evaluation-dementia-projects-minority-ethnic-communities

Flexibility in use of grant

The importance for carers of having flexibility in using their small grant was very clear, particularly because during the pandemic, carers' needs could change very quickly. Being able to change a funding request in light of changed circumstances, such as the death of the person they were caring for, was key to ensuring that carers were able to meet their specific needs through the Fund.

Uncomplicated and fast payment

The turnaround for payment of funds was quick and uncomplicated. After the decision meeting, applicants were contacted as soon as possible to inform them that their application was successful. They were invited to contact the Trust directly to provide their bank details, and payment was made at the earliest opportunity. Successful applicants were not required to provide receipts or other evidence of appropriate spend – the grants were awarded with complete trust.

> **"I think I was a little bit surprised that you didn't require the receipts but that adds to the simplicity of it, the fact that there is a funding application and then you are just expected to say that you got it. It's amazing that we do feel trusted."**

What did we learn about supporting carers during a pandemic and beyond?

Funding for technology often provided opportunities for carers to connect or reconnect with family and friends, carer support groups and online activities and sessions organised for people with dementia and carers, helping to reduce social isolation. Through the work of the Trust's Peer Support projects we know that peer support helps carers to feel listened to and understood, supported to face the challenges of caring for someone with dementia and to feel connected to others with similar experiences. Although online support was not suitable for everyone, it became a lifeline for many carers during the pandemic. Ensuring that carers have access to funding and technology to enable them to stay connected is key to reducing social isolation and supporting mental health.

At a time when gardens became a focal point for people to meet, the funding also provided many carers with the means to improve access to their gardens and outdoor spaces, enabling them to meet safely with other people and maintain social connections that could support them with their caring responsibilities. COVID restrictions highlighted the importance and value of face-to-face connections for carers and it is important that carers have the time and space to foster these relationships which help them to continue with their caring role.

Improving/maintaining physical wellbeing and health

The funding provided carers with access to exercise within or close to their home by enabling them to purchase exercise equipment that could be stored at home. This allowed them the opportunity to fit exercise around their caring responsibilities, reducing stress levels, improving sleep patterns and improving their physical and mental health and wellbeing. Exercise was also a respite for many carers.

Carers are aware of the connection between physical and mental health and recognise the importance of maintaining their own health to be able to continue caring for the person with dementia. One of the key benefits of the Fund was providing the financial means for carers to reduce stress, for example, by way of massage treatments, counselling sessions or respite through a short break or through covering the cost of care. Massage helped to reduce tension, pain and stress levels for carers but often the cost of regular massage treatments is prohibitive. Flexibility in Self-directed Support payments would enable carers to pay for regular health and wellbeing treatments, helping them to look after their own health and preventing them from reaching crisis point.

Improving/maintaining mental health

It is notable that a global pandemic has exposed the immense pressure that unpaid carers experience on a daily basis and has brought some recognition of the enormous value they contribute to society. Carers told us that the funding helped them to feel acknowledged, valued and appreciated. It gave carers hope that they had not been forgotten and often provided a boost in difficult circumstances. We learned that carers want to be given recognition for the difficult job that they do and that feeling valued and listened to can foster a sense of wellbeing.

Funding also gave carers the opportunity to pursue hobbies that had been laid aside due to time or financial constraints, providing a coping mechanism to deal with the challenges presented during the COVID pandemic. Many of the items that carers applied for related to creative activities which provided a means of relaxation and a way to manage stress and anxiety. Carers benefited from the respite provided through these activities, they enjoyed learning new skills and having something for themselves. Many carers benefited from outdoors activities in the garden, relishing fresh air and a connection with nature which served as a restorative balm.

The findings of a survey carried out by the Health and Sport Committee at the Scottish Parliament in August 2020[26] found that during the pandemic respondents were unable to use personal budgets 'to buy additional equipment such as a tablet, or art supplies in lieu of workers being available or to 'pay a family member' when carers were not available.' The impact of the Caring for the Carer Fund demonstrates the importance of a flexible approach to funding focussed on outcomes in providing carers with access to what they most need to support them.

---

[26] https://archive2021.parliament.scot/S5_HealthandSportCommittee/Inquiries/Care_at_Home_Survey_Results_Nov_2020.pdf

Carers need information and signposting to financial support

We have learned that many unpaid carers are struggling financially and are relying on funding from charity to fund essential items to support them in their caring role.

Many of the items that carers applied for, including adaptations to their homes, should be provided through statutory resources. Financial support as part of post-diagnostic support for carers would support carers in their own right to continue in their caring role.

Carers need information, especially about their rights

Often, carers who applied to the Caring for the Carer Fund were unaware of how to access support or funding and did not have an Adult Carers Support Plan in place. Research carried out between 2018 and 2020 found that many unpaid carers are unaware that it is possible to access Self-directed Support[27]. This has significant implications for the commitment in the Dementia and COVID-19 Action Plan[28] that relates to ensuring that carers are aware of and can access the support they are entitled to and are aware of their rights under the Carers (Scotland) Act 2016.

Carers need post-diagnostic support and not just for one year

The findings from the funding programme highlight the gaps in delivery of post-diagnostic support for unpaid carers during COVID and illustrate how carers are still not considered in their own right. During the pandemic local community organisations were able to respond more quickly and provide a breadth and depth of support that statutory organisations were unable to do.[29] To ensure that the needs of unpaid carers and the person they care for are met at the right time and in the right way requires a broader approach to the delivery of post-diagnostic support, at the heart of communities, with collaboration between statutory and voluntary/community organisations. Dementia Friendly Communities[30] and Meeting Centres[31] are examples of how support can be delivered within communities by a range of partners working together to improve the lives of people living with dementia and unpaid carers.

---

[27] https://www.sdsscotland.org.uk/mysupportmychoice/

[28] https://www.gov.scot/publications/dementia-COVID-19-national-action-plan-continue-support-recovery-people-dementia-carers/

[29] https://www.lifechangestrust.org.uk/sites/default/files/publication/files/BOTH%20PROGRAMMES%20COVID-19%20LEARNING%20REPORT_0.pdf

[30] https://www.lifechangestrust.org.uk/dementia-friendly-communities-evidence-and-learning

[31] https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-research/uk-meeting-centres.aspx

Contact information

If you would like any further information about this report, please contact:

Andrena Faulkner, Evidence and Influencing Co-ordinator:

andrena.faulkner@lifechangestrust.org.uk

Fiona Wynde, Senior Evidence and Influencing Officer:
fiona.wynde@lifechangestrust.org.uk

Our website: www.lifechangestrust.org.uk

Twitter: @LifeChangesTrst

WILLIAM GRANT
FOUNDATION

life
changes
trust
Creating better lives.